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ABSTRACT

This hearing, held in Brooklyn, New York, on the reauthorization of the early intervention and preschool programs of the Individuals with Disabilities Education Act, addresses the at-risk factors that prevent school readiness of young children and seeks to ascertain the extent to which at-risk children have been identified and served. A statement by Representative Major R. Owens notes that only 10 of the 50 states intend to serve at-risk children under Part H of this legislation and calls for testimony to assist in encouraging more states to serve these children. The testimony includes statements, letters, and supplemental materials from: (1) representatives of government agencies such as New York State Education Department and New York Office of Public Health; (2) representatives of private and voluntary organizations and associations, such as Citizens Committee for Children of New York, Quality Education for Minorities Network, National Association for Perinatal Addiction, Just Kids, Children's Defense Fund, National Center for Children in Poverty, and New York State Parent Committee for the Education of Children with Handicapping Conditions; (3) representatives of special schools and intervention programs including the Miriam de Soyza Learning Center and the Hebrew Institute for the Deaf and Exceptional Children; (4) representatives of universities, including the University of Massachusetts Medical Center and Rutgers University's JFK Center for Infants with Disabilities; and (5) concerned parents. (JDD)

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# FIELD HEARING ON THE REAUTHORIZATION OF THE EARLY INTERVENTION AND PRESCHOOL PROGRAMS UNDER THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

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## HEARING

BEFORE THE

SUBCOMMITTEE ON SELECT EDUCATION

OF THE

COMMITTEE ON EDUCATION AND LABOR
HOUSE OF REPRESENTATIVES

ONE HUNDRED SECOND CONGRESS

FIRST SESSION

HEARING HELD IN BROOKLYN, NY, MAY 6, 1991

**Serial No. 102-17**

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# FIELD HEARING ON THE REAUTHORIZATION OF THE EARLY INTERVENTION AND PRESCHOOL PROGRAMS UNDER THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

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MONDAY, MAY 6, 1991

House of Representatives,
Subcommittee on Select Education,
Committee on Education and Labor,
*Brooklyn, NY.*

The subcommittee met, pursuant to notice, at 4:18 p.m. in the auditorium of Clara Barton High School, 901 Classon Avenue, Brooklyn, New York, Hon. Major R. Owens [Chairman] presiding.

Members present: Representatives Owens and Payne

Staff present: Pat Laird, Maria Cuprill, Wanser Green, and Sally Lovejoy.

Chairman Owens. The Subcommittee on Select Education will come to order.

There has been a delay in the arrival of Congressman Donald Payne. However, if there is no objection we will proceed. No objection.

Recently the President unveiled his "America 2000" educational proposal to move the national education goals ahead. Among them is goal number one that our children should begin school ready to learn. And beneath that goal are a number of objectives which call for starting the process of preparing children for school, even before birth.

Although I applaud the initiative and find many positive aspects to the President's proposals, the proposals fall short of projecting the kind of overwhelming effort needed for the transformation of American education.

We need to start first at the front end of that transformation, and that means preventive and early intervention strategies and services. Unless we start at birth, many of our children will not be ready for school.

It only seems appropriate during this reauthorization that we address the at-risk factors that prevent school readiness.

Two recent reports, "Every Child a Learner" by the Education Commission of the States, and "Five Million Children" by the National Center for Children in Poverty provide some alarming facts.

Fact No. 1: About 6.9 percent or 260,000 children each year are born at below-normal rates. These children are at particularly at-risk for visual and auditory impairments and learning disorders.

Poor women are more likely to deliver these low birthweight babies.

Fact No. 2: Around 40,000 babies per year are born with fetal alcohol effects resulting from alcohol use during pregnancy.

Fact No. 3: Drug abuse during pregnancy affects about 11 percent of newborns every year causing developmental delay and learning difficulties. AIDS is now the ninth leading cause of death among children 1-4 years of age.

Fact No. 4: Poor children are exposed to higher doses of lead in their environment than are other children. The highest prevalence of lead poisoning has been recorded for poor black children living in decaying inner-city neighborhoods.

It is clear that an investment in early childhood programs is critical to the prevention of later educational failure. Only through early intervention services, screening, diagnosis and treatment, can these children be given any hope of successful educational outcomes.

At our last hearings we were told that only 10 of the 50 States intended to serve at-risk children under Part H. New York State was not one of those 10 States. Six of them will serve both biologically and environmentally at-risk children.

Unless we mount an overwhelming effort, comparable to fighting and winning a war, our society will be forced to deal with the care and treatment of unhealthy children who will grow up with long-term disabilities or have difficulty becoming self-supporting adults.

The testimony presented today will ascertain the extent to which at-risk children have been identified and served, and will assist us in making decisions that would encourage more States to serve these children.

[The prepared statement of Hon. Major R. Owens follows:]

OPENING STATEMENT OF
HON. MAJOR R. OWENS, CHAIRPERSON
SUBCOMMITTEE ON SELECT EDUCATION

FIELD HEARING ON THE REAUTHORIZATION
OF THE EARLY INTERVENTION AND PRESCHOOL PROGRAMS
UNDER THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

BROOKLYN, NEW YORK
MAY 6, 1991

RECENTLY, THE PRESIDENT UNVEILED HIS "AMERICA 2000" EDUCATION PROPOSAL TO MOVE THE NATIONAL EDUCATION GOALS AHEAD. ALTHOUGH I APPLAUD THE INITIATIVE AND FIND MANY POSITIVE ASPECTS TO THE PROPOSAL, IT FALLS SHORT OF PROJECTING THE KIND OF OVERWHELMING EFFORT NEEDED FOR THE TRANSFORMATION OF AMERICAN EDUCATION. WE NEED TO START AT THE FRONT END OF THAT TRANSFORMATION, AND THAT MEANS PREVENTIVE AND EARLY INTERVENTION STRATEGIES AND SERVICES. UNLESS WE START AT BIRTH MANY OF OUR CHILDREN WILL NOT BE READY FOR SCHOOL. IT ONLY SEEMS APPROPRIATE DURING THIS REAUTHORIZATION THAT WE ADDRESS THE AT-RISK FACTORS THAT PREVENT SCHOOL READINESS.

TWO RECENT REPORTS--"EVERY CHILD A LEARNER" BY THE EDUCATION COMMISSION OF THE STATES AND "FIVE MILLION CHILDREN" BY THE NATIONAL CENTER FOR CHILDREN IN POVERTY--PROVIDE SOME ALARMING FACTS:

- ABOUT 6.9% OR 260,000 CHILDREN EACH YEAR ARE BORN AT BELOW-NORMAL WEIGHTS. THESE CHILDREN ARE AT PARTICULARLY HIGH RISK FOR VISUAL AND

AUDITORY IMPAIRMENTS AND LEARNING DISORDERS. POOR WOMEN ARE MORE LIKELY TO DELIVER LOW-BIRTHWEIGHT BABIES.

- AROUND 40,000 BABIES PER YEAR ARE BORN WITH FETAL ALCOHOL EFFECTS RESULTING FROM ALCOHOL USE DURING PREGNANCY.

- DRUG ABUSE DURING PREGNANCY AFFECTS ABOUT 11% OF NEWBORNS EVERY YEAR CAUSING DEVELOPMENTAL DELAY AND LEARNING DIFFICULTIES. AIDS IS NOW THE NINTH LEADING CAUSE OF DEATH AMONG CHILDREN 1-4 YEARS OF AGE.

- POOR CHILDREN ARE EXPOSED TO HIGHER DOSES OF LEAD IN THEIR ENVIRONMENT THAN ARE OTHER CHILDREN. THE HIGHEST PREVALENCE OF LEAD POISONING HAS BEEN RECORDED FOR POOR BLACK CHILDREN LIVING IN DECAYING INNER-CITY NEIGHBORHOODS.

IT IS CLEAR THAT AN INVESTMENT IN EARLY CHILDHOOD PROGRAMS IS CRITICAL TO THE PREVENTION OF LATER EDUCATIONAL FAILURE. ONLY THROUGH EARLY INTERVENTION SERVICES, SCREENING, DIAGNOSIS AND TREATMENT, CAN THESE CHILDREN BE GIVEN ANY HOPE OF SUCCESSFUL EDUCATIONAL OUTCOMES. AT OUR

LAST HEARINGS WE WERE TOLD THAT ONLY 10 STATES INTENDED TO SERVE AT-RISK CHILDREN UNDER PART H; SIX OF THOSE WILL SERVE BOTH BIOLOGICALLY AND ENVIRONMENTALLY AT-RISK CHILDREN. UNLESS WE MOUNT AN OVERWHELMING EFFORT, COMPARABLE TO FIGHTING AND WINNING A WAR, OUR SOCIETY WILL BE FORCED TO DEAL WITH THE CARE AND TREATMENT OF UNHEALTHY CHILDREN WHO WILL GROW UP WITH LONG-TERM DISABILITIES OR HAVE DIFFICULTY BECOMING SELF-SUPPORTING ADULTS.

THE TESTIMONY PRESENTED TODAY WILL ASCERTAIN THE EXTENT TO WHICH AT-RISK CHILDREN HAVE BEEN IDENTIFIED AND SERVED, AND ASSIST US IN MAKING DECISIONS THAT WOULD ENCOURAGE MORE STATES TO SERVE THESE CHILDREN.

Chairman **Owens**. We have a list of invited witnesses, but we shall also extend the hearings, on an open mike basis to any guests who would like to testify following the invited witnesses.

We'll begin with panel 1 consisting of Mr. Tom Neveldine, Assistant Commissioner, Education of Children with Handicapping Conditions, and Dr. Allan Noonan, Office of Public Health, Albany, New York. Mr. Neveldine will be accompanied by other staff. No? Dr. Allan Noonan, Office of Public Health, Albany, and Mr. Steve Held from Just Kids, Middle Island, New York.

We're laboring today under a bit of a handicap with only one mike that amplifies, so please pass the mike from witness to witness.

We'll start with Mr. Neveldine.

## STATEMENTS OF TOM NEVELDINE, ASSISTANT COMMISSIONER, EDUCATION OF CHILDREN WITH HANDICAPPING CONDITIONS; DR. ALLAN NOONAN, OFFICE OF PUBLIC HEALTH, ALBANY, NEW YORK; AND STEVE HELD, JUST KIDS, MIDDLE ISLAND, NEW YORK

Mr. **Neveldine**. Thank you Chairman Owens. I appreciate this opportunity to provide testimony regarding the provision of special education in New York State.

Since the New York State Department of Health is the lead agency for implementation of programs under Part H, representatives of that agency will fully comment on those programs. Mr. Edmund Cortez of our department will, however, provide testimony for the record.

I'm here today for really a secondary purpose, not only to talk a little bit about preschool but to address the progress that has been made in regard to the compliance issues in the New York City education system.

So I was wondering if you'd like me to begin with that overview or if you prefer to talk about the preschool area.

Chairman **Owens**. You may begin with what ever is——

Mr. **Neveldine**. Okay. Let me give you a quick synopsis, I've provided testimony for the record, just to bring you up to date on where we are.

The most long-standing issue in New York City's special ed programs has been the waiting list for evaluation and provision of instructional and related services. This issue goes back before Public Law 94-142 and has been the subject of ongoing litigation for over 12 years under the Jose P. court case.

We've been actively involved in working with the plaintiffs and working with the New York City Board of Education to bring a resolution to these compliance problems over the past 12 years and particularly have been very active in the past two.

We've been withholding the IDEA-B funds, formerly known as the EHA Part B funds, for the 1989-90 and 1990-91 school years pending the resolution of the compliance issues.

To insure that the current progress that we've been seeing in recent months continues, key staff members of the department including Deputy Commissioners Meano and Walton, have been meeting on a monthly basis with members of the board, and we have been reviewing all the compliance issues. So I just want to go through those very quickly.

First, in terms of the waiting list for evaluation, the current executive director of the division, Mr. William Rojas, under his leadership we've seen significant progress, which is included in Attachment A, in terms of the waiting list for evaluation.

Just as an example, the list of students awaiting evaluation for more than 30 days in September was 8,605. That's been reduced as of February to just slightly over 4,000. Awaiting placement for more than 60 days was over 20,000 in September and that's been reduced to 6,500 as of the end of February.

The one area that continues to be problematic is the waiting list for related services which was at 10,100 at the end of September and is currently, as reported the last figures at the end of January, was 11,600. So the shortages in the area of speech, physical therapy, occupational therapy and bilingual staff have a significant impact on the lack of progress in that area and we've been working with the board. However, in the other areas we are seeing progress.

We are also discussing with the City University of New York and working with the board, ways in which we can train and get more qualified bilingual staff members especially into the system. And we're considering now grant proposals and the use of discretionary funds to start up some new programs in the city.

The second issue deals with absent paraprofessionals and absent resource room teachers. We've had a problem in that when these staff members have been absent for long periods of time there hasn't been coverage. These have been the subject of some of our ongoing discussions with the city. They both relate to important provisions included in students' Individualized Education Programs and obviously have to be provided for.

We have received a plan for the coverage of paraprofessionals now from the city which has been deemed acceptable so we'll be monitoring that implementation. We are still awaiting a plan for coverage for resource room teachers when they're absent for long periods of time.

The third issue deals with transporting students who are attending non-public schools to neutral sites for special ed services. This has been another issue that's been long-standing with the city. The board has acknowledged its legal obligations now for those students and has agreed to develop a plan and we expect to receive that plan by the end of May.

Item 4 deals with consultant teacher services. This particular service in special education became part of New York State's continuum services in 1988 but has not been implemented yet by the New York City Board of Education.

We have provided some discretionary funds for pilot projects even in advance of that becoming part of the continuum and did receive the approved plan in June 1989.

However, that plan has still not been implemented. The board has agreed to submit a revised plan by September for implementation in September 1992.

One of the other major changes we're making in terms of resources and staffing is that in our New York City regional office we're going to be allocating at least 40 percent of our discretionary funds now for our technical assistants activities to assist the city in coming into compliance. One example is we have 50 special education training and resource centers around the State, that's currently about a $6 million project statewide. New York City currently receives about $1.3 million. That grant is going to be increased to $3 million next year.

And similarly with other kinds of grants that are available through our Office of Technical Assistance, we are going to insure that an equitable proportionate share of those resources are devoted to the New York City office and also maintain and augment our current ongoing monitoring in each of the compliance issues on a monthly basis.

And we believe that the current progress is promising. However, we know we need to continue to monitor and to provide more technical assistance in order for the city to get into compliance and to sustain that compliance.

And finally, one other issue that we've been reporting as an area of concern in our report to the governor each year deals with the overrepresentation of Blacks and Hispanics in special education. This particular issue we know on an aggregate basis, we have a problem in our State. Unfortunately, we like many States, have not collected the appropriate data in terms of our annual child count to the Federal Government and identifying specifically the race of the students and in some cases the gender.

So in a current survey done by the National Association of State Directors they indicated that only 23 States currently collect that information on the child count that's reported to the Federal Government by race so obviously we have some work to do in that area.

We also intend to conduct a study to see if we can determine what the causes of the overrepresentation are in terms of particular regions in the State. So that kind of brings you up in a very quick summary in terms of our activities in New York City.

Chairman **Owens**. You also noted that you want to make some comments on Public Law 99-457.

Mr. **Neveldine**. The 3 to 5 portion I'd like——

Chairman **Owens**. And you also have testimony submitted by Lawrence C. Gloeckler? Is that from your department also?

Mr. **Neveldine**. Yes. And Mr. Cortez is here to address any questions. However, that responsibility is really the Department of Health's in our State, so perhaps you want to defer some of the testimony, the presentation to them and then I'll pick up with the 3 and 5 year olds.

Chairman **Owens**. Do you want Mr. Gloeckler's statement to be entered fully——

Mr. **Neveldine**. Yes.

Chairman **Owens**. [continuing] for the record I assume.

Mr. **Neveldine**. Yes.

Chairman **Owens**. Without objection, we'll enter Mr. Gloeckler's statement into the record along with your statement.

Mr. **Neveldine**. Okay.

Chairman **Owens**. You may make any remarks you wish in addition to that.

Mr. NEVELDINE. Okay. I just wanted to make a few quick comments in regard to our preschool program which was enacted into legislation July of 1989 which deals with 3 and 4 year old children with handicapping conditions.

We've recently developed a legislative proposal to assist us in being better prepared for the entitlement this July 1991, and I just want to highlight some of the changes we're recommending to the legislature to improve the current service delivery system and position ourselves for that entitlement on a statewide basis.

First of all, the eligibility criteria is one of the issues. In our legislative proposal we're providing broad language and I realize there's a current discussion going on in terms of the 3 year age as being a firm date upon which the child has the transition or be in and funded by the 3 and 4 year old portion of the preschool system.

We, like many States, believe there should be more flexibility obviously in determining when that 3 year age should be implemented, and we're providing broad enough language in the legislation so that if the Federal Government does change their mind on that, we can accommodate either way but we will be in compliance with it.

One of the major issues in the preschool program for us, and major issues of debate, I guess, over the last few years we've been implementing, has been the issue of eligibility and a classification scheme for that. We currently have the 11 handicapped conditions similar to what we have in school age in terms of identifying children who would be eligible for that system.

And there's been a lot of discussion, not only by the Commissioner's Advisory Panel for Special Education but other groups among the State who have an interest in this program, about looking at whether or not classifications such as learning disabled and emotionally disturbed make sense for children who are 3 years of age, 4 years of age or whether we should look at some other kind of a system.

So in response to that, our legislation talks about having public hearings on the issue and also consulting with our advisory committees and then bringing regulations under the commissioner's authority in March of 1991 for implementation in July of 1992. So, in other words, it would give us one more full year.

We're also looking at providing more flexibility. We've had difficulty in terms of having enough evaluation capacity under the preschool bill. And currently to be an evaluator you have to also be in an approved program and that's caused some problems in terms of cutting out some of the clinics and hospitals and other agencies that have previously been involved in doing evaluations.

So our proposal really seeks to reinstitute that flexibility and allow school districts or approved programs or clinics to be evaluators. And as a companion piece we would set a separate rate for those to encourage that to occur. So we think that will be helpful.

Another change we're making is to allow related services to be provided at more locations determined by the Board of Education. Currently a child would have to be in a nursery school or a day care school to get a related service such as occupational therapy or speech therapy. And we found that in some low-income areas families cannot afford day care and so it works against them in terms of getting services to their child.

So our proposal would allow the Board of Education to allow related services to be provided at family day cares at the site of a provider, at a clinic, and really expanding the range including, in some unique cases, even the home so that all children can take advantage of the services.

And finally, we're looking at—in terms of least restrictive environment—to put a focus on the preschool's multi-disciplinary team to look at related services first before they look to more restrictive programs; full day kinds of programs for children to make sure that with the new flexibility we're using the itinerant services or related services to the maximum degree before children get in more restrictive programs.

So that's the substance of the legislation we proposed. And I'm sure other individuals will be commenting on the 3-4 year old system. Thank you very much.

[The prepared statements of Tom Neveldine and Lawrence Gloeckler follow:]

No. 2

Statement of

New York State Board of Regents
and the New York State Education Department

to

The Subcommittee on Select Education
Committee on Education and Labor
U.S. House of Representatives

with respect to

IDEA, Part H and
Special Education Compliance in New York City

May 6, 1991

Presented by:

Thomas B. Neveldine
Assistant Commissioner
New York State Education Department
Office for Education of Children with Handicapping Conditions

Chairman Owens and Subcommittee Members:

I appreciate this opportunity to provide testimony for the New York State Education Department on the provision of special education in New York State. Since the New York State Department of Health is the lead agency for implementation of programs under Part H, representatives of that agency will comment fully from their perspective. Our Department has provided testimony for the record and Mr. Edmund Cortez will respond to any questions regarding our testimony. I would like to address the progress that has been made in some of the problematic areas relating to special education in New York City and to outline the status of each of the major outstanding compliance issues and the steps that the Education Department is taking in order to resolve these issues.

The most long-standing issue in New York City's special education programs has been the waiting list for evaluation and the provision of instructional and related services. This is an issue which antedates the implementation of P.L. 94-142 and which has proven relatively intractable despite interventions by the state court system, the Commissioner of Education, and finally the Eastern District Federal Court as a result of the Jose P.v. Sobol case. The continued existence of the waiting list has, in fact, resulted in two contempt findings against the New York City Board of Education by Judge Eugene Nickerson, the judge presiding in the Jose P. case, the most recent of these occurring in June, 1990.

The New York State Education Department has been actively involved in trying to resolve the waiting list and other serious compliance problems over the past twelve years and has been particularly active in the past two. As indicated to Chairman Owens in a letter from Commissioner Sobol on August 10, 1990, the Department has been withholding the city's IDEA-B funds for 1989-90 and 1990-91 pending the completion of certain carefully defined activities. To date, these funds have not been released, although it appears that some of the identified issues have been resolved and that the city is making progress on others. To ensure that this progress continues, staff members of the Department, led by our Deputy Commissioners for elementary and secondary education programs, have met with key Board of Education staff on a monthly basis to review the issues item-by-item and to receive monthly progress reports. Commissioner Sobol will be meeting with Chancellor Joseph Fernandez in the near future to outline the specific conditions for release of the Federal funds for 1989-90, 1990-91 and 1991-92 and to reaffirm the joint responsibilities of the Board of Education and the Department in resolving the long-standing compliance issues in special education and the related Jose P. litigation. Follow-up meetings will be held with the Board of Regents and the plaintiffs in that litigation to ensure all responsible parties are clearly apprised of the steps which need to be taken in this matter.

I would like to provide you with the current status of each unresolved issue and give you a brief overview of our Action Plan.

1. Waiting Lists for Evaluation and Delivery of Services.

The current Executive Director of the Division of Special Education, newly appointed in September, 1990, has been able to make significant progress in reducing waiting lists for evaluation and placement. (The data delineating the progress from September, 1990 through February, 1991 are attached as Appendix

A.) The most significant gains have been made in evaluating and delivering services in a timely fashion to monolingual English speaking students. While some progress has been made in evaluating and delivering timely services to children whose primary language is other than English, a shortage of appropriately trained personnel who also speak other languages and have the requisite background in bilingual education or English as a Second Language has made this a more difficult problem to resolve. The long-term solution will be to train more people with skills in other languages in the needed areas of special education.

Discussions are currently underway with branches of the City University to encourage them to increase their program offerings in bilingual special education and other special education shortage areas. It is our hope to be able to provide funds for program development, as well as to provide some scholarships to qualified candidates who would commit themselves to working in New York City's special education programs for a specified period of time following the completion of their training.

2. Coverage for Absent Classroom Paraprofessionals and for Absent Resource Room Teachers

These are both issues that relate to the implementation of students' Individualized Education Programs (IEPs). Until recently, when a paraprofessional assigned to a special education classroom was absent or when a student's resource room teacher was absent for an extended period, these absences were not covered, despite the fact that the associated services were included in students' IEPs. At the present time, a plan for covering paraprofessionals' absences has been implemented as of early April, 1991. A plan for covering the absences of resource room teachers is being developed. The implementation of the plan addressing paraprofessional absences and the continued development and subsequent implementation of the plan addressing resource room teacher absences will be monitored to assure that full compliance is achieved.

3. Transportation of Students Attending Non-public Schools to Neutral Sites for Special Education Services

This issue remains unresolved. However, some progress has been made in that the Board of Education has acknowledged its legal obligation to provide such transportation and has agreed to develop a plan by the end of May,1991 for identifying the eligible students and transporting them in a manner consistent with that prescribed in their IEPs.

4. Implementation of Consultant Teacher Services

Consultant teacher services became part of the continuum of services for students with disabilities in New York State in 1988. The intention of this legislation and

> its implementing regulations was to increase the opportunities for New York's disabled students to be educated in regular education classes with their non-disabled peers while receiving the special education to which they were entitled. New York City has been reluctant to implement this part of the continuum for a variety of reasons, despite receiving a grant of discretionary funds to pilot this model in one community school district and also despite a plan for implementation which was approved in June 1989. Following a recent meeting with Department representatives, staff of the Board of Education agreed to submit a revised plan by September, 1991 for implementation no later than September, 1992.

The Department plans to significantly augment the resources available from Federal funding sources to strengthen the capacity of our New York City Regional Office in addressing the ongoing compliance issues in special education. The additional funds will be used to assist the office in expanded oversight of the compliance problems, and, also, to work collaboratively with the New York City Board of Education to bring the City into compliance and to sustain compliance.

We remain confident that with continued and augmented monitoring, training, and technical assistance being provided by the Department, the progress we have seen in New York City over the past year will be maintained. We will continue to meet with the Chancellor's key staff to work toward creating the conditions under which a long-term positive turn-around in the provision of special education programs and services in the

New York City region can occur.

It must be noted a significant area of concern exists in addition to the compliance issues outlines above: the overrepresentation of Blacks and Hispanics in special education. According to New York, the State of Learning: A Report to the Governor and the Legislature on the Educational Status of the State's Schools for 1989-90, "The statistics clearly demonstrate [on an aggregate basis] the overrepresentation of Blacks and Hispanics in ungraded, self-contained special education classes". The Department will be conducting a study to investigate the causes of this overrepresentation. On the basis of those findings, recommendations will be made regarding appropriate next steps.

Thank you for allowing me this time to outline for you our perspective on special education in New York City. I shall be happy to answer any questions that you might have.

Appendix A

## NEW YORK CITY WAITING LIST UPDATE

| | 9/90 | 10/90 | 11/90 | 12/90 | 1/91 | 2/91 |
|---|---|---|---|---|---|---|
| Awaiting evaluation 30 + days | 8,605 | 5,213 | 4,823 | 3,048 | 3,651 | 4,192 |
| Awaiting placement 60 + days | 20,070 | 10,940 | 8,498 | 8,074 | 7,205 | 6,508 |
| Awaiting related services | 10,100 | 10,600 | 10,746 | 11,853 | 11,622 | NA |

No.3

Statement of

New York State Board of Regents
and the New York State Education Department

to

The Subcommittee on Select Education
Committee on Education and Labor
U.S. House of Representatives

with respect to

Reauthorization of Part H, Public Law 99-457

May 6, 1991

Submitted by
Lawrence C. Gloeckler
Deputy Commissioner
New York State Education Department
Office of Vocational and Educational Services
for Individuals with Disabilities

## TESTIMONY ON THE REAUTHORIZATION OF PL 99-457, PART H

We thank you for the opportunity to present the views of the New York State Education Department regarding the reauthorization of the Part H of the Individuals with Disabilities Education Act (IDEA), program for infants and toddlers with disabilities.

Since the enactment of the Federal Law, the New York State Education Department has been committed to working with other State agencies, parents and providers in developing a comprehensive, multidisciplinary system of early intervention services for children with disabilities, birth to two, and their families. PL99-457, Part H provides the framework and impetus to stimulate all agencies to work toward insuring a comprehensive array of services for young children with disabilities and their families and toward developing a system which will avoid duplication of services and be easily accessible to families.

In contrast to the previous emphasis on single agency approaches to service delivery and finances, the process described in PL99-457, Part H has been a major challenge for States, including New York. At the time Congress established Part H, it was believed that five years would be sufficient time for States to achieve the goals established in the law. New York State has made substantial progress towards putting a system in place which meets the requirements of the law. However, the task at hand is far more complex and challenging than was originally thought, particularly since existing resources are insufficient to make services available on a full entitlement basis. The assumption that sufficient resources were available and that Federal funding would be adequate is no longer the case. Further complicating the funding situation is the deteriorating condition of State budgets, a problem which could not have been anticipated in 1986.

The New York State Education Department strongly recommends that amendments to Part H be made to allow those States which have not been able to meet the requirements of the fourth or fifth year applications, but have demonstrated good faith efforts, be allowed to continue to participate in the Part H program for up to three additional years and receive funding during this period. This additional time would enable States to convince legislative leaders to implement the Part H system and to work with the wide array of state and local agencies to construct the complex and comprehensive system required under this statute. States could be asked to document, in their applications for funding, the progress that has been made regarding the implementation of the required components of the system, the identification of the barriers encountered which has impeded progress, and a plan and schedule for meeting the requirements necessary for full implementation.

It is essential that Congressional support of increased appropriations continue as States move from planning to implementation of the program, especially given the serious fiscal conditions in the States. The commitment shown by Congress in the past has been appreciated by States and has been important, not only as a sign of support, but also as a source of revenue to assist States in providing services to children with disabilities, birth to two. This commitment in the form of additional resources must continue.

A related issue is the allocation of Part H funds. Specifically, consideration needs to be given to whether allocations in the long term should be determined on the basis of the estimated number of infants and toddlers to be served or on the basis of child count. Our Department recommends that this be addressed in the next reauthorization of Part H after all States have reached full implementation.

Additionally, financing for Part H needs to be carefully studied over the next several years as States attempt to coordinate funding across multiple private, State and Federal sources. The identification of obstacles to fully funding statewide systems, specifically barriers resulting from policies mandated in Federal programs, would assist in determining how adequate financing can be achieved. Further, we agree with the recommendations of the National Association of State Directors of Special Education (NASDSE) and others, that the role of assigning financial responsibility among the agencies which provide early intervention services should be assigned to the State rather than the lead agency for Part H.

The New York State Education Department also recommends that amendments to Part H be made which would allow the States to define the technical age of three in order to ensure and facilitate a smooth transition from services under Part H to those funded under Part B Section 619. This flexibility is necessary so that States can insure that children approaching age three receive services under either Part H or Part B, thus allowing for appropriate planning on the part of agencies at the State and local levels. It would assure smooth program transitions rather than abrupt program transitions on the child's third birthday.

As part of the reauthorization, we recommend that States be provided with flexibility in making services available for at-risk children under Part H. Allowing States to provide a more limited array of services, at their option, to at-risk children who may not be eligible under the state's eligibility criteria, would be desirable. This is consistent with recommendations made by NASDSE.

We also recommend that States be allowed to claim funds for handicapped infants and toddlers under PL89-313, Chapter I, during the development of a statewide comprehensive and coordinated system consistent with PL99-457, Part H. Eligible children under PL89-313 should not have funds denied on their behalf as States transition from their current birth to two system to one which meets full compliance with the law. Such funding would appropriately help cover the costs of delivering services to these infants and toddlers with disabilities.

The Federal Interagency Coordinating Council (FICC) can play a significant role in facilitating the Federal coordination of programs authorizing services for infants and toddlers with disabilities and their families. This coordination at the Federal level would assist the efforts of States in their delivery of services. We recommend that the FICC make recommendations to Federal agencies which would enhance collaboration, eliminate interagency barriers, and make recommendations to Congress regarding issues which may require statutory changes. To facilitate this coordination at the Federal level, the revised statute should require that a policy analysis be conducted of other relevant Federal programs to determine areas of conflict which overlap with Part H, and recommend solutions.

In closing, we recognize the advances made by States in moving toward full implementation of this important statute and believe that the changes we are recommending will allow this process to continue in a smoother, coordinated fashion.

Chairman Owens. Thank you. At this point I'd like to yield to my colleague, Mr. Payne, for an opening statement.

Mr. Payne. Thank you very much, Mr. Chairman.

First of all, let me apologize for being late. If we were on the Public Works and Transportation Committee, maybe we could adjust some of these problems getting through from New Jersey to New York and I suppose vice versa. But since we are not there, I hope you would accept my apology for being late.

I would just like to commend you for calling this hearing on the individuals with the Disabilities Education Act which, as we know, is a Federal law which provides for the education of disabled infants, toddlers, children and for particularly focusing today on the at-risk children.

Over the past decade there has been a dramatic increase in the number of environmentally and biologically at-risk children. Many of them are suffering from prenatal alcohol or drug exposure, some of them are the victims of child abuse and neglect, and some of them are the innocent victims of AIDS.

We must encourage the space to assist the children and their families by providing the necessary educational programs and support services and we must continue to provide adequate support and funding for these programs at the Federal level.

Mr. Chairman, hopefully through the services that can be provided for at-risk children we can begin to identify as early as possible which children need the services and we can begin to help them and their families as they try to become as independent productive as they can possibly can.

I look forward to hearing all the witnesses. And the first one certainly shed some interesting light on the subject. Thank you, Mr. Chairman.

Chairman Owens. Thank you.

Our second witness is Dr. Allan Noonan from the Office of Public Health.

Do you have staff accompanying you, Dr. Noonan?

Dr. Noonan. Yes, I do. I'm accompanied by Mr. Frank Zollo, who is the Director of Early Intervention with the State Department of Health.

Chairman Owens. The name again?

Dr. Noonan. Frank Zollo, Z-o-l-l-o.

Chairman Owens. Thank you.

Dr. Noonan. We appreciate this opportunity to speak to you regarding the Reauthorization of the Program for Infants and Toddlers with Disabilities. First, I'd like to briefly describe the progress New York State has made with this program and the barriers that we've faced.

Then I'd like to make some specific recommendations.

This act has caused us in the State of New York to reevaluate our services to the population of infants and children and agree upon a definition of early intervention. For us in New York State early intervention is not a social, medical nor educational service. It is a developmental program that blends all services needed by a child and family to insure that each child reaches his or her fullest potential.

New York State is proud of its long history of commitment to services to these children. Since 1976 families in the State have had the ability to petition Family Court to pay for services for their young children with special needs.

When families are successful in the petitioning process, the end result is a court order requiring the county of residence and the State to pay for all services within the petition.

Through the Family Court Program numerous services for children with disabilities have been developed primarily within the voluntary sector. Over the years as more services have become available for this population of children, the growth in State and local expenditures related to the Family Court Program has been significant.

In the current fiscal year, when we are not required under Part H to serve a single child or family, we will spend in excess of $120 million in State and local funds through the Family Court.

One could ask why New York State chose to participate in Part H given the current provisions for services, and we have been asked that question. The most important answers to that question are programmatic.

First, although services are available for children with disabilities in the State, the manner in which those services are selected and delivered in many instance, but not always, lacks the essential family-centered focus embodied in Part H, and in particular, the concept of the individualized family services plan.

Secondly, currently children in New York State and their families have limited opportunity to receive services within the context of their homes and in their general community setting. We feel that the incentive Part H offers for provision of services in these normalized settings is essential to promote the development potential of all children and especially for children under the age of 3 years.

Thirdly, access to services funded through the Family Court differs dramatically across the State and is largely dependent upon factors external to a child's needs, such factors as the county in which a family resides and the judge to whom their petition for services is submitted.

Only 32 percent of all children who received these services funded through the Family Court resided in New York City, for example. Yet 43 percent of all children under 3 years of age lived in the city and arguably many of these children are at highest risk for developmental problems here in New York City. Part H creates not only an entitlement to early intervention for eligible children but also a mandate for child find.

And fourthly, services funded through the Family Court are not regulated by any State agency making quality assurance largely dependent upon the good faith efforts of the providers and making due process for the families an impossibility.

The greatest challenge for New York State has not been fiscal but rather has been to reach consensus about how best to build upon the foundation of existing services while at the same time bring about the fundamental systems reform and service delivery changes that are at the heart of Part H.

We've tackled this problem by starting with the premise that a grass roots planning process, one that would involve families, service providers and the local governments potentially most affected by Part H, would be the key to our success.

Our first important step was to appoint an expanded Interagency Coordinating Council of 35 members, seven of whom are parents of children with special needs. We also used a significant part of our first three years of Part H funding to create and maintain a network of 11 Regional Planning Groups, RPG's, staffed by paid parent and professional coordinators and comprised of parents, service providers, local government officials and other interested citizens. The RPG's have been an effective vehicle for local involvement in the statewide planning process.

Perhaps our greatest achievement through the RPG's has been the significant participation of parents in local planning. Through the able leadership of the RPG's a powerful State consensus has emerged that the new early intervention system must be family driven, parent-empowering and flexible enough to accommodate the unique and evolving needs of developing infants and toddlers and their families within the State.

In addition to these activities, the State has contracted with the three University Affiliated Programs to provide statewide technical assistance to the Regional Planning Groups, the Interagency Coordinating Council and other agencies involved in the planning process.

This interactive process is culminating in the introduction of a Governor's Program Bill in 1990 to establish the New York State Early Care Program. Unsuccessful in 1990, a refined version of this legislation has been reintroduced in 1991 with improved chances of passage.

Some key features of this bill are multiple opportunities for child find of eligible children, identification and tracking of at-risk children, implementation of individual services plan, case management services and the use of Medicaid and third party insurance to fund early intervention services.

It must be noted that the realities of fiscal constraints have forced us to make the difficult choice to limit eligibility for early intervention services to children with evidence of developmental delay, disability or a condition with a high probability of resulting in development delay.

However, the Department of Health as the State's lead agency for early intervention services has signaled a strong commitment to the implementation of a comprehensive child find effort beginning at birth and an ongoing monitoring of all children's growth and development as a routine part of child health care.

The Department of Health intends to implement a comprehensive new child find program to identify, locate and monitor infants and toddlers at-risk for developmental problems. It's ongoing commitment to the statewide Infant Health Assessment Program, referred to as IHAP, established in 1984, will be strengthened, however. This program, IHAP, also provides for identification screening, provision of service, referrals and follow-up of infants and young children at-risk for developmental problems.

Children registered in IHAP receive home visits, developmental screenings at six months and 2 years of age, family needs assessments, and information and referral services from public health nurses.

In upstate New York counties a total of 38,000 children have been registered in IHAP and 47 percent of these children continue to be served. In New York City 5,000 of the 23,000 children ever registered to the program continue to received IHAP services.

The city IHAP program has made identification and tracking of infants born to mothers with substance abuse problems a high priority. This population has clearly been identified as one at great risk for developmental problems.

In addition, the State agencies are collaborating on the newborn focus Neighborhood-Based Initiatives and the New York/New York Connect effort. These are joint efforts by the governor, Governor Cuomo and Mayor Dinkins and are promising interagency efforts targeting 15-20 specific high need communities for intensive development of coordinating services of human service delivery. Mothers and infants and their families residing in these communities will be a priority.

Finally, I'd like to make two specific recommendations for changes in the current statutory provisions. Department staff indicate that many other States agree with these proposals.

The first is that Part H appropriation be significantly increased. We are under no illusion that Part H would be a major source of funding for our statewide early intervention system. A substantially strengthened Federal commitment is essential, however, as States assume in future years the burden of an entitlement to appropriate services for all eligible children and their families. The New York State Department of Health feels that the proposed 4 percent increase for fiscal year 1992 is grossly inadequate.

The second recommendation is to provide a mechanism for differential participation by States not ready to create an entitlement to services in year five. States which have not met all requirements for year four should receive their Part H allocation if they can demonstrate substantial progress. States which have implemented their system statewide but cannot create an entitlement by the end of year four, should be allowed an additional two years to develop that entitlement.

We look forward to your prompt action in reauthorizing Part H, and thank you very much for the ability to present before the subcommittee today.

[The prepared statement of Dr. Allan Noonan follows:]

**Testimony of Allan S. Noonan, M.D.**
**Associate Commissioner for New York City Affairs**
**New York State Department of Health**
**to**
**U.S. House of Representatives**
**Subcommittee on Select Education**
**Brooklyn, New York**
**May 6, 1991**

Chairman Owens and members of the subcommittee, my name is Dr. Allan Noonan and I am the Associate Commissioner for New York City Affairs of the New York State Department of Health. I appreciate this opportunity to speak to you regarding the reauthorization of the Program for Infants and Toddlers with Disabilities, Part H of the Individuals with Disabilities Education Act.

First, I will briefly describe the progress New York State has made with this program and the barriers we have faced. Then I will indicate our specific recommendations to you in reauthorizing Part H.

When New York State elected to participate in this important program in 1987, we jointed all fifty states, the District of Columbia, and four territories in a common quest for better futures for families and their very young children with special needs. To reach this goal, Part H requires us to create a new and different "category" of service: early intervention. Early intervention is not a social, medical, or educational service: it is a developmental service that blends all services needed by a child and family to ensure that each child reaches his or her fullest potential.

Part H also demands those of us concerned about these children and their families -- from state policy makers to community service providers -- to rethink our approaches to and goals for the service delivery system. Specifically, Part H compels us to:

- involve families as meaningful partners in decisions related to services their child and family unit receive and in the provision of those services;
- include consumers as key participants in planning and implementing the early intervention service system; and,
- coordinate the planning, delivery, and funding of early intervention services across the multitude of state and local, public and private agencies involved in and responsible for services to infants and toddlers with special needs.

These key concepts, which on the surface sound self-apparent and simple, are as monumental to implement as are the benefits that will be reaped by families and their children. Every state is encountering unique hurdles in planning for the implementation of Part H -- and New York State's continue to be many.

Certainly, the fiscal impact of this program has been and will continue to be a topic of lively discussion in New York State. Yet in comparison to other states, we are in a better position to make an argument that we can afford -- and in fact cannot afford not to -- implement Part H.

New York State is proud of its long history of commitment to services for children with disabilities. Since 1976, families in this state have had the ability to petition Family Court to pay for services for their young children with special needs. When families are successful in the petitioning process, the outcome is a court order requiring the county of residence and the state to pay for all services within the court petition. Through the Family Court Program -- which is essentially a funding stream, not a program -- numerous services for young children with disabilities have been developed, primarily within the voluntary sector.

Over the years, as more services have become available for this population of children, the growth in state and local expenditures related to the Family Court Program has been significant. In the current fiscal year, when we are not yet required under Part H to be serving a single child or family, we will spend in excess of $120 million in state and local funds on infants and toddlers through Family Court.

One could ask why New York State chose to participate in Part H given the current provisions for services. And we have been asked that question.

The most important answers relate to program philosophy:

- Although services are available for children with disabilities in New York State, the manner in which those services are decided upon and delivered often lacks the essential family-centered focus embodied in Part H and in particular, within the concept of the individualized family services plan.

- Currently, children and their families have limited opportunity to receive services within the context of their homes and typical community-based settings. We feel the incentive Part H offers for provision of services in normalizing settings is essential to promote the development potential of all children and especially for children under the age of three.

- Access to services funded through Family Court differs vastly across New York State and is largely dependent upon factors external to children's needs (such as the county in which a family resides and the judge to whom their petition for services is submitted). Only 32% of all children receiving services funded through Family Court reside in New York City, for example -- yet 43% of all children under three live here and arguably, many of the children at highest risk for developmental problems live within the five boroughs. Part H creates not only an entitlement to early intervention services for eligible children but also a mandate for child find with standardized evaluation criteria.

- Services funded through Family Court are not regulated by any state agency, making quality assurance largely dependent on good faith efforts on the part of providers and due process for families an impossibility.

The greatest challenge for New York State, then, has not been primarily fiscal in nature but rather has been to reaching consensus about how best build upon the foundation of existing services while at the same time bringing about the fundamental systems reform and service delivery evolution that are at the heart of Part H.

We tackled this problem by starting with the premise that a grass roots planning process -- one that would involve the families, service providers and the local governments that will be most affected and have the most to gain from Part H -- would be the key to our success.

Our first important step was to appoint an expanded Interagency Coordinating Council that includes both Governor and Commissioner-appointed members to ensure a breadth of representation and expertise related to services for this population. Our Council consists of 35 members, seven of whom are parents of children with special needs. From its establishment, the Council has been co-chaired by a parent and professional member -- reflecting the emphasis the Council as a body has placed on consumer involvement in all levels of planning.

We used a significant portion of our first three years of Part H funding to create and maintain a network of eleven regional planning groups (RPGs) staffed by paid parent and professional coordinators and comprised of parents, service providers, local government officials and other interested Citizens. The RPGs have been an effective vehicle for local involvement in the statewide planning process and for gathering critical information about existing resources, identifying service barriers and gaps, and policy information reflective of regional concerns.

Perhaps our greatest achievement through the RPGs has been the significant participation of parents in local planning efforts. New York State is fortunate to have many dedicated parents participating in the eleven Regional Planning Groups. Through their able leadership, a powerful state consensus has emerged that the new early intervention service system must be family driven, parent-empowering, and flexible enough to accommodate the unique and evolving needs of developing infants and toddlers and their families who will receive services through this system.

Appreciating the federal government's establishment of a national technical assistance arm to assist states with their early intervention activities, the Department of Health has contracted with the three University Affiliated Programs in New York State to provide statewide technical assistance to the Regional Planning Groups, the Interagency Coordinating Council, and the state agencies involved in the planning process. Among the many contributions our Statewide Technical Assistance Resource Network has made to this project has been the implementation of an extensive needs assessment examining the status of early intervention services, evaluating family satisfaction with the current system and their assessment of unmet needs, and identifying personnel training needs statewide.

Part H funds have also enabled the staffing necessary to manage this complicated planning process: we have a core team within the Department dedicated to early intervention and in addition, have provided funds to ten state agencies to promote an informed and inclusive interagency planning process.

This interactive planning process culminated in the introduction of a Governor's Program Bill in 1990 to establish the New York State Early Care Program. Unfortunately this bill was not acted on by the Legislature last year. The Governor's Office has continued to work with the state agencies and the Interagency Coordinating Council to revise and refine the EarlyCare legislative proposal for introduction in 1991.

The emerging fiscal crisis in New York State, however, presented another significant hurdle to overcome before finally securing the successful submission of a Governor's Program Bill on EarlyCare to the New York State Legislature on April 2, 1991. As lead agency, we were confident that the passage of the EarlyCare legislation would not only result in significant improvements in services for children and families but also in substantial financial savings for the State and localities. To prove our point, we prepared an extensive fiscal analysis elucidating the cost-benefits of EarlyCare over the current Family Court Program. Chief among the factors identified in this analysis as reducing current service costs were the opportunity to more flexibly tailor services to meet children and families' actual needs and the ability to tap Medicaid and third party reimbursement as funding sources.

Our presentation of the fiscal issues was persuasive, but we largely owe the introduction of the legislation to the effective efforts of our Interagency Coordinating Council, parents and professionals involved in the eleven Regional Planning Groups, major advocacy organizations in New York State - including the Citizen's Committee for Children of New York, State Communities Aid Association, Statewide Youth Advocacy, and the newly-created Communities Concerned for EarlyCare, and a growing constituency on behalf of early intervention services.

Some key features of the EarlyCare legislation include provisions for:

- multiple opportunities for child find, screening, and referral of eligible children to early intervention services;
- identification, location, screening and tracking of at risk children populations;
- flexibility and parent choice in the amount and location of early intervention service delivery through the development of individual family service plans (IFSPs) for each eligible child and family;
- significant family participation in the service delivery process and service system;
- care coordination (case management) services to assist eligible families with the evaluation process and coordinate the development of individualized family service plans;
- due process procedures for families, including mediation;
- use of Medicaid and third party insurance as payment sources for early intervention services with sufficient protection for family insurance policies to ensure no out-of-pocket charges; and,

designation by municipalities of a county human service agency to act in the capacity of local administrator of the early intervention service system.

We are pleased with the fruits of our joint labor and hopeful that the New York State Legislature will act on the Governor's EarlyCare bill to enable our continued participation in the Part H program. It would be regrettable indeed if New York State was forced to withdraw from the Part H program when we have come such a long distance toward implementation of a statewide early intervention service system.

Before offering specific recommendations related to Congressional reauthorization of Part H, I want to briefly address where New York State stands on the issue of entitlement to early intervention services for at-risk children and their families.

Among the many difficult issues states have struggled with in establishing the required policies for implementation of Part H, none has been harder than the decision about whether to create an entitlement to services for infants and toddlers at risk for developmental delays and disabilities. These children and their families include many of our most vulnerable and often disenfranchised populations: among them are low-income families disengaged from the traditional service systems, with a disproportionate share being minorities, victims of family violence and neglect, and families raising children in inadequate housing or families who are homeless. Although the threat to children's development posed by these and other risk factors has been acknowledged by all participants in New York State's planning process, the realities of immediate fiscal constraints have forced us to make the difficult choice to limit eligibility for early intervention services to children evidencing a developmental delay, disability, or condition with a high probability of resulting in developmental delay, rather than investing in the future for children at risk of disability and their families.

However, we believe that the Governor's action to designate the Department of Health as the State's lead agency for early intervention services has signalled a strong commitment to the implementation of a comprehensive child find effort beginning at birth and in particular, to strengthening efforts which ensure ongoing monitoring of all children's growth and development as a routine part of child health care and public health responsibility.

The Department of Health intends to implement a comprehensive child find program that will provide for the identification, location, and monitoring of infants and toddlers at risk for developmental problems. Our intentions are invigorated our ongoing commitment to the statewide Infant Health Assessment Program (IHAP), first established in 1984 to enable the identification, screening, provision of service referrals, and follow-up of infants and young children at risk for health and developmental problems.

Children registered in IHAP receive home visits, developmental screenings at six months and two years of age, family needs assessments, and information and referral services from public health nurses. In upstate New York counties, a total of 38,041 children have been registered in IHAP and 47% of these children continue to be followed by IHAP public health nurses. In New York City, 5,771 of the 23,081 children ever registered to the program continue to receive IHAP services. The City IHAP program has made identification and tracking of infants born to mothers with substance abuse problems a priority -- a population of children clearly at risk for developmental problems.

Of course, there is opportunity for improvement -- including refinement of the eligibility criteria for children's enrollment in IHAP; we see Part H as the impetus and vehicle for broadening the eligibility net and increasing the effectiveness of the program. Our child find efforts, however, are not limited to programs under the auspices of the Department of Health. Effective coordination of the myriad of services offered by other state agencies which have the potential for identifying and locating children will be an important part of our efforts to screen and monitor children at risk.

The Neighborhood-Based Initiative and New York/New York Connect, a joint effort of Governor Cuomo and Mayor Dinkins, are also promising interagency efforts targeting some 15 - 20 specific high-need communities for intensive development of coordinated human services capacity. Mothers and infants and their families residing in these communities are a priority.

I turn now to two specific recommendations for changes in the current statutory provisions. Department staff tell me that these recommendations are widely shared by other states.

1. The Part H appropriation must be significantly increased. We are under no illusion that Part H will be the source of the majority of funding for our statewide early intervention system. A substantially strengthened federal commitment is essential, however, as states assume, in future years, the burden of an entitlement to appropriate services for all eligible children and their families. The President's proposed 4% increase for FFY 92 is grossly inadequate and does not begin to invest in the potential of these children and their families.

2. Provide a mechanism for differential participation by states not ready to create an entitlement to services in Year 5. States which have not met all requirements for Year 4 should

receive their Part H allocation if they can demonstrate substantial progress. States which have implemented their statewide system but not created an entitlement should be permitted to continue at the Year 4 level for up to two additional years.

We look forward to your thoughtful and timely action in reauthorizing Part H. Thank you for the opportunity to address the Subcommittee today.

Chairman Owens. Thank you, Dr. Noonan.

Did Mr. Zollo want to make any comments?

Mr. Zollo. No, thank you, Mr. Owens. I'll be glad to respond to questions afterward if there are any.

Chairman Owens. The next witness is Mr. Steve Held of Just Kids, Middle Island, New York.

Mr. Held. Mr. Chairman and members of the subcommittee. I am Steve Held, executive member of the New York State Association of Private Schools and Agencies for Exceptional Children, executive board member of Long Island Coalition for Children with Special Needs and executive member of New York State Division of Early Childhood and the Director of Just Kids Early Childhood Learning Center.

I appreciate the opportunity to speak before you on behalf of children from birth to five with developmental disabilities and their family members in New York, and in support of the reauthorization of the Early Intervention and Preschool Programs under the Individuals with Disabilities Education Act.

I have areas of concern, however, about the implementation of this program in my State, New York. Specifically these concerns are the impact on parental choice, the erosion of regional municipal authority based on New York's interpretation of Public Law 99-457, New York's definition of eligibility criteria based on its interpretation of Public Law 99-457 eligibility categories, and the need for programmatic and eligibility maintenance of effort provision in Federal law.

Since 1975 New York State has served children from birth to five with handicapping conditions under the Family Court Act. This law entitled parents to choose the appropriate program to provide services for their handicapped child. Municipalities were responsible for administration and program accountability. Overall programmatic authority was invested in the State Education Department.

If providers were unresponsive to parent needs for their children, parents moved their children to other programs. Although problems existed in the system, parent empowerment insured the quality of individual programs through healthy competition.

After Public Law 99-457 passed, without grandfather or maintenance of effort provisions, States like New York with previously working systems, found themselves technically out of compliance with the new Federal statute. In New York it was determined that municipalities could not assume the role designated for LEA's under the statute and that the Family Court system did not afford due process.

The result was lengthy and emotional with philosophical battles over parental choice versus parental right. Parents asserted that choice was far more empowering than rights. Municipalities also demanded a substantial say in the program if they were to continue providing 50 percent of the funding.

Although Representative Owens and Senator Harkin and their very responsive staffs clarified congressional intent so as to allow the New York system to continue, Federal and New York State Educational Departments failed to recognize the articulately written statements from both Houses. As a result, New York legislated a new statute on July 3, 1989 to comply with the Federal Education Department's mandates.

Children began attending programs under the new law on July 5th of that same year. The new State legislation replaced parental choice with parental rights and eroded the input allowed to municipalities. We are still trying to develop the new systems; kinks are being ironed out daily.

The new oversight and accountability measures in the law resulted in more, not fewer, children identified as handicapped, which has alarmed the New York State Division of Budget in the wake of this State's fiscal crisis. The State contends that IDEA allows them to modify the system further. We are awaiting new reduction measures in the pending Mandate Relief Bill. It is stated that the proposed bill will save approximately $120 million. This represents 50 percent of the total program cost.

In my county of Suffolk, officials estimate that 70 percent of the children now receiving services will be deemed ineligible under the Mandate Relief Act. Without a programmatic and eligibility maintenance of effort at the Federal level, parental choice will again be limited, municipal input will be further decayed, and eligibility criteria will be so restrictive that the concept of productive early intervention will be lost forever in New York.

The greatest irony is that these destructive actions are being taken in the name of IDEA. What Congress created in 1986 to provide programs for handicapped infants and preschoolers who are receiving no assistance, is now being used in New York State to dismantle what was in 1986, a $260 million program.

The only way to assure that no more children are denied vital services and that there is no further deterioration to the system, is for the Federal Government to mandate, as a condition for receiving Federal funds, that States maintain the same level of funding and eligibility for these programs that they have in the past.

Without a maintenance of effort provision, children in New York become the victims of IDEA instead of its beneficiaries.

Thank you for all you time on our children's behalf over the years, Mr. Chairman, and staff member, Pat Laird.

I will be happy to answer any questions you might have. Thank you.

[The prepared statement of Steve Held follows:]

No. 5

Statement of

Steve Held

Executive Board Member of

New York State Association of Private Schools and
Agencies for Exceptional Children

Long Island Coalition for Children with Special Needs

Coalition of Parents, Teachers and Schools

New York State Division of Early Childhood

Executive Director
Just Kids Early Childhood Learning Center

To

Hon. Major R. Owens, Chairperson

House Subcommittee on Select Education
on

Hearings on the Reauthorization

of the Early Intervention and Preschool Program

Under the Individuals with Disabilities

Education Act

P.L. 99-457

May 6, 1991

**Statement by Steve Held on Reauthorization of the Early Intervention and Preschool Program under the Individuals with Disabilities Education Act.**

Mr. Chairman and Members of the Subcommittee:

I am Steve Held, Executive Member of the New York State Association of Private Schools and Agencies for Exceptional Children and the Director of Just Kids Early Childhood Learning Center. I appreciate the opportunity to speak before you on behalf of children from birth to five with developmental disabilities and their family members in New York, and in support of the reauthorization of the Early Intervention and Preschool Programs under the Individuals with Disabilities Education Act (IDEA).

I have areas of concern however, about the implementation of this program in my state, New York. My concerns include:

(1) the impact on parental choice;

(2) the erosion of regional municipal authority based on New York's interpretation of P.L. 99-457;

(3) New York's ability to redefine eligibility criteria based on its interpretation of P.L. 99-457 eligibility categories; and

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(4) the need for a "Maintenance of Effort" provision in Federal law.

As you know, since 1975, New York State has served children from birth to five with handicapping conditions under our "Family Court Act." This law entitled parents to choose a program for evaluation and possible treatment of their handicapped child. The responsibility of the administration and accountability of this program was placed with the municipality in which the child resided. Overall programmatic authority was the responsibility of the State Education Department. Fourteen Child Find "Direction Centers" were financed and administered by the State Education Department throughout our state. Parents could access services from multiple points and were empowered to have a substantial say in their child's intervention strategies. If program providers were not responsive to parents' needs for their children, they were excluded from servicing children in the future. Although problems existed in the "system", parent empowerment ensured individual program efforts toward healthy competitive quality. Localities throughout the state developed regional implementation regulations in order to ensure accountability and program integrity.

After P.L. 99-457 passed without "grandfather" or "maintenance of effort" provisions, states like New York (who had comprehensive service delivery systems for developmentally disabled children already in place) found themselves "technically" out of compliance with the new Federal statute. In

New York State it was determined that an LEA (Local Education Agency) could not be a municipality (although California does consider it so, and is still in compliance) and that the Family Court did not afford "due process rights."

Philosophical battles raged between parents and the New York State legislature. Parents argued that "choice" is far more empowering than "right" and Municipalities argued that a fifty percent financial responsibility for the program entitled them to substantial say in the complex and "expensive" system.

Congressman Owens, Senator Harkin and their very responsive staffs clarified Congressional intent; however, Federal and New York State Education Departments failed to respond to these articulately written statements from both Houses. New York had three months to develop, legislate and implement a new system from "scratch." On July 3rd, 1989 New York legislated a new statute to comply with the Federal Education Department's mandate. Our implementation date was July 1, 1989 with children attending programs on July 5, 1989. Parents from all over New York State mourned their hard fought loss, but vowed to continue to advocate for their children's and their own rights; rights to which they were previously entitled. From the summer of 1989 to the fall of 1990 our parents' providers, and administrative agencies all went "crazy" trying to help this new system develop. "Kinks" are still being ironed out daily. Much more work must be done. New oversight and accountability measures resulted in more, not fewer, children identified as handicapped. This result alarmed our Division of Budget. Our state's fiscal crisis demanded mandate relief and our developmentally disabled children from birth to five were again targeted.

Letters like the one that follows were sent by thousands of providers and parents to our state's leadership . . .

> "We are writing because we need your help! Two years ago, the Legislature enacted sweeping changes in the procedure for evaluating and placing pre-school children. These changes were wrenching, particularly because they limited the parents' choice in selecting the program that the parents believed was best for their children. Nevertheless, parents and schools agreed to the new oversight and accountability measures out of a spirit of compromise and a willingness to work with the State and counties to effect improvements in the system.
>
> Now the Governor and the Division of the Budget propose to undo all of that and reduce parent choice even more. Worse, they propose changes that would make ineligible thousands of children who clearly and indisputably have handicapping conditions. Under the criteria proposed by the Governor, a three-year old child would need to show a one-year delay -- a developmental delay of one-third of the child's life! -- In two functional areas before being eligible for services. What kind of system would this create? Children with IQ's of 70 would no longer be eligible. Children with major speech and communication disorders would no longer be eligible. Children with major behavioral and learning disabilities would no longer be eligible. We would have an early childhood system in which children could receive services until they turn three at which point they "graduate" into nothing. Then after they spend the next two years regressing, they enter the school system with greater learning and developmental delays that require much costlier special education.
>
> Worst of all, these changes would not result in a single penny of cost savings to the State in the upcoming fiscal year. The changes proposed in S.3018/A.4518 are NOT necessary to implement the budget!
>
> We recognize the State's dire fiscal condition and are more than willing to work with the Division of the Budget, the counties and your staffs to find savings. We estimate that millions of dollars can be saved through more efficient administration and by making portions of the system Medicaid-eligible.
>
> What the Governor has proposed is wrong. It is wrong for children and their families who will be denied desperately needed-services. It is wrong for counties, whose taxpayers

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> will ultimately have to bear huge additional special education costs. And it is wrong for the State, which will also be forced to bear the huge additional costs that will result from denying handicapped children an opportunity to overcome their disabilities at an early age -- an age where intervention has the greatest impact."

Now in the spring of 1991 we are again awaiting our legislators' response to us and pending legislation. Our State government continues to cite IDEA as the statute which they can legally follow to again decimate our system and provide minimal services for our developmentally delayed children. In the memorandum of support for this "Mandate Relief Bill" it is stated that one-hundred and fifty million dollars would be saved by this legislative action. This represents fifty percent of our total program! In my county, Suffolk, officials estimate that 70% of our children will be deemed ineligible. Without a "maintenance of effort" provision in P.L. 99-457 parent choice will again be limited, municipal input will be further decayed, and eligibility criteria will be so restrictive that the concept of early intervention will be lost forever in New York!

The greatest irony is that all these destructive actions are being taken in the name of IDEA. What Congress created in 1986 to mandate programs for handicapped infants and preschoolers who are receiving no assistance, is now being used in New York State to dismantle what was, in 1986, a two hundred and sixty millon dollar program. The only way to assure that no more children are denied vital services and that there is no further deterioration to the system, is for the Federal government to mandate, as a condition for receiving Federal funds, that States maintain the same level of funding for these programs that they have in the past. Without a "maintenance of effort" provision, children in states like New York become victims of IDEA instead of beneficiaries.

Thank you for all of your time on our children's behalf over the years, Mr. Chairman and Staff Member Patricia Laird.

Testimony

before

The Division of Early Childhood (DEC) -
Council on Exceptional Children (CEC)
Governmental Relations Committee

Mesa, Arizona

prepared by

Steven Held
Director

JUST KIDS
an early childhood learning center

Middle Island,
New York

February 4, 1990

Good Morning, Distinguished Members of the Committee. I am Steven Held, the legislative chairperson of the New York State D.E.C. The N.Y.S. D.E.C. includes parents, school district personnel, private providers, college faculty and other professionals involved in both the education and medical support of children in N.Y. I am also the Director of JUST KIDS, an Early Childhood Learning Center, located in Middle Island, Suffolk County, New York. JUST KIDS has been in operation for 10 years and serves both handicapped and non-handicapped children from birth to age five. We are currently serving 460 children, 350 of whom have disabilities. My purpose in appearing before you today is to explain the effect that the implementation of P.L. 99-457 has had on handicapped preschool children in New York State.

My testimony is divided into three parts. Part 1 explains the difficulties experienced by parents, children, and preschool providers in the implementation of P.L. 99-457 and the uncertain future we face. Part 2 explains why there were complications with the way P.L. 99-457 was formulated by the U.S. Congress and administered by the U.S. Department of Education. The final section contains recommendations for amendments to the federal law that would assist the New York State program.

PART 1 -- DIFFICULTIES IN IMPLEMENTING P.L. 99-457

Before the signing of Public Law 99-457, The Education of Handicapped Children's Act Amendments of 1986, New York State routinely served handicapped children from birth through five years of age and had done so in many regions for 25 years. Between the State government and the individual counties in New York State over $250 million dollars were spent annually on preschool handicapped programs.

Although we supported the passage of P.L. 99-457 for children throughout the country, we were concerned about its impact on the New York State delivery system. While our system was not perfect, it went far beyond the mandates of P.L. 99-457 in providing services to handicapped children and protections for parents in choosing what was best for their children. Rather than oppose the bill outright, we attempted to advocate technical changes in the law that would preserve the qualities in our system that seemed to mirror Congressional intent -- if not specific statutory language -- in P.L. 99-457. In the months that followed the passage of the Act in October, 1986, a delegation from New York diligently responded to U.S. Department of Education regulations. Our goals are embodied best in a resolution adopted by New York State's Division of Early Childhood (NYS/DEC). In relevant part, that document stated:

> "New York State has a history of providing such educational services through a network of diverse voluntary programs. The availability of a range of programs and the work of the Direction Centers have facilitated access to effective special education

and allied services. In addition, parents have had the unique opportunity to play the major role in their child's placement.

"Therefore, NYS/DEC strongly recommends that any changes in the administration and delivery of services to children from birth through five in NYS must guarantee:

"1. Preservation and support for the existing network of educational programs provided by voluntary agencies (Private, non-profit, public); and

"2. Continuation of the principle of parent choice and free access to all appropriate services.

"In summary, NYS/DEC recommends that a downward extension of regulations for school age children not be applied to the unique needs of children birth through five with handicapping conditions."

Specifically, we were trying to maintain four features of the pre-October, 1986 system: parent partnership; a continuum of services for children birth to five; equal access to programs, public and private; and continued summer programming for preschool handicapped children.

Our efforts to obtain adequate federal help to preserve our program failed. The New York State legislature enacted new legislation on July 3, 1989, with implementation beginning immediately on July 5th, 1989. That legislation voided the idea of parental choice. It substituted choice of the evaluation site and time consuming, costly "due process" provisions in place of the former concept. Parents are no longer free to choose the appropriate program for their own child.

Additionally, it disrupted the 25 year old system of providing a continuum of services to handicapped children, birth through five years of age, by assigning administrative responsibility for children from birth through two years, eleven months to the Department of Health, and placing three to five year olds under the jurisdiction of the State Department of Education.

Depending on the regions in New York State, the State-passed legislation also gives purpose to the creation of programs for handicapped preschool children through the public school systems. By 1991 rather than expanding the existing system of a combination of private and public providers of services, school districts may be mandated to open there own program. This undermines programs that have been in existence, in some cases, for more than two decades. These same programs have evolved in time to the point where children are successfully integrate both non-handicapped and handicapped children in one environment. Because services for non-handicapped preschoolers are not offered in most public school systems, the proposed public school-based program will at best provide separate, not integrated, environments for handicapped children.

Finally, the new legislation contains cumbersome requirements for summer programs that threaten to deny many eligible students the opportunity to attend school this summer.

(For your information, a copy of a letter explaining the problems in summer school programs is attached.)

It is ironic that the intent of P. L. 99-457 was to maximize a handicapped child's potential in order to minimize their need for supplemental services when they entered public school. In New York State, it has served to disrupt a system that fulfilled that intent and replaced it with one in which many children will go inadequately served or unserved until they are school age.

Seven months after the implementation of our State legislation, the majority of handicapped children and their families have reason to feel uneasy about their futures. Federal P.L. (89-313) dollars for our handicapped children between birth and age three have been discontinued and federal P.L. 94-142 dollars for three to five year olds have been held up indefinitely. Not only have programs been disrupted, but both private and public program providers have reason to question their ability to stay in business.

PART 2 -- PROBLEMS WITH P.L. 99-457

The problems that we are currently experiencing in New York State are directly attributable to the enactment of P.L. 99-457 and its implementation by the U.S. Department of Education. The legislation did not include four specific provisions that could have prevented the problems we now face. These are --

1) New programs should have been modeled after existing successful programs for preschool handicapped children, not after school age programs. (L.E.A. funding requirement)

2) State programs that were already in existence at the time the Act was enacted should have had their statutes considered in compliance if their system substantially met the "intent of the law"

3) The definition of "due process" should have been broadened to include systems that provided a higher standard for parental involvement, such as total parental choice.

4) A provision should have been included in the statute that would have required existing State programs to maintain at least the same level of fiscal support for handicapped preschool programs, as they did before passage of the Act, in order to receive funds from the new federal program.

To begin with, the major flaw in P.L. 99-457 is its attempt to model a program for preschool handicapped children by extending downward the program for school-aged handicapped children. Clearly there are no mandates in the New York State public education system for serving any preschool youngsters. When other Education of the Handicapped Children Acts were adopted, it was a matter of making available to handicapped children the same public school programs already available to their non-handicapped counterparts. This is not the case with preschool children. It would have been far more practical to review successful preschool programs that were already in place in some states, such as New York, and using them as the model for new programs.

A second problem with the way the legislation was written is that it failed to protect States who had had programs which were already providing services for preschool handicapped children. A provision should have been included which would have allowed these State programs to continue to function without major change -- a grandfather or hold harmless provision, if you will. This is clearly a frequently used vehicle to ensure program integrity and would have gone a long way in preventing the disruption that has occurred in New York.

A third troublesome area concerns the concept of "due process." If there are no existing programs, or if a program does not allow parental involvement, it is clearly necessary that "due process" provisions be mandated. However, when a situation exists, as it did in New York, in which a higher standard -- in this case total parental choice -- is already in place, it should have been exempted from change.

The last provision that should have been included in the law is a mandate that States maintain at least the same level of funding under the new legislation as they were providing prior to its implementation. Among the many complicated problems that faced us in implementing the new law in New York was the desire of the

State government to use the State legislation that was passed to control the State government's cost for preschool programs by serving children during traditional 10 month programs but questioning previously 12 month placements.

Although P.L. 99-457 was far from perfect, once we explained the problems it was causing us, its Congressional authors were very receptive to providing clarifications of their intent in writing the legislation. This would have allowed either the U.S. Department of Education or New York State's Education Department to accept our delivery of services. However, in spite of numerous phone calls, letters and official interpretations from Congressional staff and the Congressmen who wrote the Act, both the State and Federal Departments of Education persisted in dismantling New York's preschool program.

Unfortunately for New York State's handicapped children, we were unable to get a "hold harmless" amendment to the federal statute that would have specifically allowed continuation of the New York system in its pre-1986 form. As a result, the U.S. Department of Education Office of Special Education Programs determined (in spite of Congressional opinion to the contrary) that New York was out of compliance with the new law, and issued funding withdrawal letters. Furthermore, the New York Department of Education used the federal law as its justification to rewrite its program.

Perhaps the cruelest irony is that after we had several meetings with the Department of Education in Washington, D.C., the officials in charge refused to allow the continuation of the New York preschool program, because it was out of compliance. They did instead approve draft legislation, which was later passed by the State in June, which modeled the preschool program after the existing public school program. However, since that time, Federal Education Department officials have ruled that the school age program is also out of compliance. Therefore no federal funds are now available in New York State for handicapped preschool children.

In short, the handicapped youngsters of New York have fallen through a very big crack, created by good intentions, poorly focused legislation, perplexing bureaucracies, and budget crunches. What was meant to ensure the very best services for children across the Nation, has ultimately denied those services to the children of New York State.

## PART 3 -- WHAT CAN BE DONE?

I wish I could recommend changes to federal law which could turn back the clock and allow the pre-1986 programs to once again exist in New York. That is impossible. Unfortunately, new legislation is in place and any large scale changes would only serve to cause even more delays in providing desperately needed services. With the fragile infants and young children with whom we work, every day, week or month's delay decreases their potential to grow into prosperous, contributing adults. Enough time has already been wasted and too many children have already been harmed.

However, I would encourage the Congress to make at least one change. A provision should be added to P.L. 99-457 which would require States to return to a minimum of the 1988-89 funding level for preschool programs, before they can receive federal funding. While this will not alter the new and burdensome requirements for due process and other activities, it will at least ensure increased, not decreased, funding for preschool programs -- clearly, a Congressional intent to begin with.

Thank you for this opportunity to testify. I will be happy to answer any questions you might have.

Chairman OWENS. Thank you. I want to thank all the panelists and begin by asking Dr. Noonan if he'd like to respond to Mr. Held.

Dr. NOONAN. Well, I think that I did indicate that the program, IHAP, has done some significant work in the past several years in trying to identify developmentally disabled children. And the growth of that program in the past year was significant. I believe we doubled the allocation to that program.

I also am surprised to hear that he feels that children would be left out when we in the city have seen this as an opportunity to bring in more children who heretofore have been unidentified by the early intervention system and bring the services that are needed. Those are my major issues. I don't know whether Frank would like to address these two issues.

Mr. ZOLLO. Well I would just clearly draw the distinction between proposed changes in New York State related to the 3 and 4 year old preschool special ed system and the governor's proposal for implementing Part H for infants and toddlers.

And, Mr. Held, correct me if I'm wrong, but I believe the thrust of his comments were directed to proposed changes in the preschool special ed program for 3 and 4 year olds.

Mr. HELD. All of my comments were for 3-4 year olds and not——

Mr. NEVELDINE. Maybe it would be appropriate if I just made a few remarks in response. In terms of the eligibility issue, I think I mentioned a few moments ago that the proposal that the department has advanced would let the commissioner determine eligibility following consultation with our advisory committees: the Commissioner's Advisory Panel for Special Education, the Preschool Advisory Committee, and the County Advisory Committee; also, after the conduct of public hearings.

In terms of the governor's proposal, we would agree it's too restrictive at this point in time and would eliminate a certain proportion of students from services.

And I think in conjunction with the proposal being advanced by the governor dealing with the whole issue of related services, those children would no longer be eligible under the special ed system.

One of the things we tried to do in our proposal is strengthen the provision of related services, provide more flexibility rather than cut the kids out of services. So I think Steve has addressed a couple of areas in which we would be supportive in terms of his perspective. And we are hopeful that the legislature will act favorably on a proposal because it will address, I think, some efficiencies needed in the system but not reduce or eliminate services for children who need services and also make sure that those eligible for the 3 and 4 year old system will continue to be eligible for it. So we don't disagree in terms of his perspective on those particular issues.

Chairman OWENS. Dr. Noonan, you said that the Neighborhood Based Initiatives and New York/New York Connect, a joint effort by Governor Cuomo and Mayor Dinkins, are also promising interagency efforts targeting some 15–20 specific high need communities for intensive development of coordinated human services capacity.

How far away is—is that in operation now, and if not in operation now, how far away is the reality of that?

Dr. **Noonan**. New York/New York Connect was implemented, went into operation on the 1st of March in three communities.

Chairman **Owens**. Of this year.

Dr. **Noonan**. Of this year.

Chairman **Owens**. In three communities.

Dr. **Noonan**. Central Harlem, Brooklyn, Bedford-Stuyvesant, and South Bronx. Those are programs to outreach, especially to drug using women. In fact, the initial focus is on women who arrive at the hospital to deliver an infant, who have a history of drug use, but no history of prenatal care. Those women are counseled, advised of services, and hopefully enrolled into the New York/New York Connect program.

The Neighborhood-Based Initiatives program has the same general focus but it has more community involvement in the planning. The prioritization is done by the community as opposed to the government agencies.

The number of communities which will be addressed by Neighborhood-Based Initiatives in New York City will probably be around six or seven, and we will probably be able to expand geographically on the New York/New York Connect effort with the Neighborhood-Based Initiative.

The proposals for the Neighborhood-Based Initiatives are in and being evaluated. The funding is expected to be allocated in July or August.

Chairman **Owens**. Who operates the hospitals or clinics? In Central Harlem, Bedford-Stuyvesant, South Bronx, what types of——

Dr. **Noonan**. The New York/New York Connect and the Neighborhood-Based Initiatives are different. Under New York/New York Connect the funding that has taken place so far has gone to the perinatal networks which are an older State Health Department program. And through these networks we are funding two positions each; one for enrollment of these high-risk women while they're in the hospital, and the other in each network for case management of these women after they are discharged.

The Neighborhood-Based Initiatives will be funded through community-based organizations depending upon how that community decides it wants to be funded. They will be funded. The money will come from the Department of Social Services.

Chairman **Owens**. So they are not operating now.

Dr. **Noonan**. Not the Neighborhood-Based Initiatives; New York/New York Connect, yes, NBI, later this year.

Chairman **Owens**. I said earlier that New York State is not a State that has chosen to serve at-risk populations. And then in your testimony you said a lot that made it a little unclear to me.

Can you clarify that for us? Identification, location, screening and tracking of at-risk populations—that's part of your program; that's what you do do? What is it that you don't do for at-risk populations?

Mr. **Zollo**. Mr. Owens, what we don't do and what we don't propose to do at this time, is to take advantage of the authorization in Part H to designate children at-risk of developmental delay as entitled to the full range of early intervention services including evaluation, IFSP, and case management.

As much as we would like to do that, the prudential judgment by the governor at this time has been that making the commitment, proposing that the State make a commitment, to go forward with creating an entitlement to early intervention for every child with developmental delay, is as much as the State can bite off given the current economic situation and a very serious State budget deficit.

Indeed, we know that we have a fight on our hands in the remaining two months of the State legislative session. We deemed in our testimony that there are existing programs, particularly in our IHAP program, that are identifying, tracking, and insuring developmental screenings for at-risk youngsters. So, we don't want to leave that population out or suggest that they're left entirely without attention.

Rather, we do acknowledge that we're not in a position, or at least the executive branch is not in a position, to afford a full range of early intervention services to at-risk children at this time.

Chairman OWENS. Well that decision was arrived at despite the fact that New York City and New York State have one of the highest concentrations of drug abuse problems to mothers and one of the highest AID death rate problems or AID case load problems.

Mr. ZOLLO. Mr. Owens, we believe that many children of substance abusing parents will be eligible for Part H services since they will not be, I'll use the term, merely at-risk but, in fact, developmentally delayed. So we look forward to serving children whose parents are substance abusers or alcohol abusers and who demonstrate developmental delay or have a diagnosed condition with a high probability of developmental delay.

We think that that's an underserved population in terms of our current service delivery system under Family Court. Dr. Noonan alluded earlier to the fact that New York City is disproportionately underserved by that system. So we think there are not just at-risk but actually developmentally delayed infants and toddlers out there that need to be identified and need to be served with a full range of Part H services.

Dr. NOONAN. I'd like to add that we intend to—we are already coordinating on New York/New York Connect effort and on Neighborhood-Based Initiatives effort with the early intervention effort. And we intend to pick up more babies through these combined efforts than through any one alone. So we have fiscal reality staring us in the face but we do realize that we have a great need in New York City to identify and track newborns of high risk.

Chairman OWENS. Fiscal reality means that we probably will have to spend more money later on children who were not identified and helped at an early stage, that's fiscal reality.

Dr. NOONAN. That's true.

Chairman OWENS. Mr. Held, did you want to make a comment on that?

Mr. HELD. I agree with you. I also wanted to say that one of the points that I was making in my testimony was not that the Department of Health hasn't been a tremendous advocate for children nor the State Education Department. I was totally against the legislation in 1989 and I found the department individuals to be very much advocates for kids.

My point was in the landmark legislation that you helped pass at the Federal level, we see a Division of Budget—not a program provider—looking to utilize that particular mandate on a Federal level to compromise the services that we have in New York State rather than enhance the services.

When the Federal Government comes out with minimal standards, I don't think that their intent, and certainly your intent, was for us to look at our program and cut it down to the minimal services. I think it should be enhanced to the point it can be.

The Mandate Relief Act makes no mistake about what its intent is: it's a mandate relief, and it's looking to save dollars on a State level, and it's looking to have many children that were otherwise eligible since 1975 become ineligible. So the individual administrative agencies within the State are excellent at advocating for children's needs.

But when the Division of Budget comes out with program bills—I wouldn't be so brave if Governor Cuomo were sitting next to me certainly right now—but I think that the intent is to save money and cut programs and that's not what the Federal IDEA's intent was from the very beginning.

Chairman **OWENS**. Thank you. Mr. Payne.

Mr. **PAYNE**. Thank you. Not being up on the New York State participation I assume that New York State has not moved forward on this Part H of the 1990—of the authorization of the Act.

Mr. **ZOLLO**. We've not yet submitted a fourth year application, that's correct.

Mr. **PAYNE**. I see. Just a general question about your action plan, I note that the commissioner indicated that you have substantially closed the waiting time on the waiting list and you have an appendix in the back that shows substantial reduction and waiting time.

How were you able to do that, with additional staff or what caused a cutting in half of the time in a six month period?

Mr. **NEVELDINE**. I think the impetus for change came from a couple of different sources. One, Judge Nickerson, in his continuing oversight of the Jose P. litigation, entered into stipulation during the summer where he encouraged the city to use procession activities to the maximum extent possible to bring the waiting list down, so that's been helpful.

Secondly, the new executive director of the Special Education Division has worked in terms of getting more efficiencies in the systems and setting some standards for the work load and production of the various evaluation teams; so, that's helped also.

And as I mentioned, we've been meeting on a monthly basis, the deputy commissioners and myself, together with staff from the monitoring division; so, we're back each month looking for the progress. So I think those things in combination have helped to bring it down.

We're hopeful that the progress can be sustained and we can eventually clear up the waiting list and move on to other issues in the city.

Mr. **PAYNE**. Also I noticed in your remarks that you said that now there will be coverage for absent classroom paraprofessionals and teachers. Currently certain types of special education or special programs do not have substitute teachers. When a teacher is absent does the child just lose out?

Mr. **Neveldine**. Right. In two ways. For instance, if there's a special class program that has a paraprofessional assigned to it because of the severity of the students involved and that paraprofessional happens to be absent for a month or two, we were not seeing the provision of substitutes. This meant that the students' IP's were not being fulfilled because they were supposed to be placed in a class that had both a teacher and a paraprofessional, because of the types of disabilities they had; so, that was part of the problem.

And, in the resource room area, which basically in New York City is a pullout, if the resource room teacher wasn't there for a period of time, it meant that the students weren't getting the supplemental instruction to assist them in benefiting from the program, so they simply weren't getting any special education services for that period of time.

So in both cases it was a failure to provide some mechanism that would provide the substitute coverage for both the teacher assistant in the one case, and the resource room teacher in the other case.

Mr. **Payne**. Thank you. I have no further questions.

Chairman **Owens**. I want to thank all the members of the panel for taking time out to come to testify. We certainly appreciate your statements. Your entire written statements will be entered into the record.

Thank you very much.

Our next panel is Dr. Dan R. Griffith, Developmental Psychologist, National Association for Perinatal Addiction, Research, and Education, Chicago; Dr. William Scarbrough, Associate Director for Research, National Center for Children in Poverty located in New York; Mr. Bernard Charles, Quality Education for Minorities Network, Washington, DC; Ms. Delia Pompa, Director of Education, Adolescent Pregnancy Prevention and Youth Development of the Children's Defense Fund, Washington; Dr. G. Gordon Williamson, JFK Center for Infants with Disabilities, Rutgers University and Ms. Marji Erickson, Associate in Pediatrics, University of Massachusetts Medical Center, Worcester, Massachusetts.

Any persons who wish to testify after this panel in the open-mike session, please give your name to the committee clerk, Ms. Green.

We'll begin with Dr. Dan Griffith.

## STATEMENTS OF DR. DAN R. GRIFFITH, DEVELOPMENTAL PSYCHOLOGIST, NATIONAL ASSOCIATION FOR PERINATAL ADDICTION, RESEARCH AND EDUCATION, (NAPARE) CHICAGO; DR. WILLIAM SCARBROUGH, ASSOCIATE DIRECTOR FOR RESEARCH, NATIONAL CENTER FOR CHILDREN IN POVERTY, NEW YORK; BERNARD CHARLES, QUALITY EDUCATION FOR MINORITIES NETWORK, WASHINGTON, DC; DELIA POMPA, DIRECTOR OF EDUCATION, ADOLESCENT PREGNANCY PREVENTION AND YOUTH DEVELOPMENT, CHILDREN'S DEFENSE FUND; WASHINGTON, DC; DR. G. GORDON WILLIAMSON, JFK CENTER FOR INFANTS WITH DISABILITIES, RUTGERS UNIVERSITY; AND MARJI ERICKSON, ASSOCIATE IN PEDIATRICS, UNIVERSITY OF MASSACHUSETTS MEDICAL CENTER, WORCESTER, MASSACHUSETTS

Dr. GRIFFITH. Thank you for inviting me. I'd like to read testimony from the National Association for Perinatal Addiction, Research and Education, which is NAPARE, in Chicago. The primary focus of NAPARE has been over the last several years the assessment of and intervention with drug-exposed infants, children and their families.

Much of what I'm going to talk about today is the result of a longitudinal prospective research study which we have had going on since April of 1986 with approximately 300 children who were prenatally exposed to drugs, the majority being exposed to cocaine usually in combination with alcohol, marijuana and/or cigarettes.

And it's our experience with this group of mothers and children that drug exposure is one of only a multitude of risk factors which may impact upon these children and their families.

The direct effects of the lifestyles of pregnant chronic substance abusers on the developing fetus usually include little or no prenatal care, inadequate prenatal nutrition, poor general maternal health and increased incidence of sexually transmitted diseases.

These factors, in combination with drug exposure, place the child at increased risk for a variety of problems, the most common of which include intrauterine growth retardation, including stunted brain growth, prematurity with its attendant problems, and an increased risk for perinatal morbidity and mortality.

Those infants we followed in NAPARE have been followed and have had many of these risk factors reduced.

Women who are in our project, enrolled in the project during prenatal care, usually during the first trimester of their pregnancy, receive both prenatal care and chemical dependence therapy. Most of them either quit using or reduced their drug use significantly during the course of the pregnancy.

The improved pregnancy outcomes of these women point out the importance of early identification and treatment of pregnant substance abuser. For those women in our program who were able to stop using cocaine during the first trimester of the pregnancy, for example, the rate of prematurity was only 17 percent as compared to 31 percent for those women who continued to use in our program, and a similar percentage of about 30 percent has been listed in other studies of other populations with no prenatal care, and also the low incidence of low birthweight among our women who got treatment and quit using during the first trimester was 0 percent as compared to 25 percent for those using throughout the pregnancy.

The cessation of cocaine used during the first trimester, however, did not improve the neurobehavioral outcome of the infants. Those infants exposed the first trimester only were equally deficient as compared to those exposed all through trimesters in terms of State regulation, motor control and interactive capabilities. This speaks to the need for drug use prevention programs as well as identification of an intervention with female substance abusers of child-bearing age prior to their becoming pregnant.

The heavily exposed newborns that we have seen can best be described as low threshold infants. What we mean by low threshold infants are infants who have trouble controlling their States so that they move from States of sleeping to screaming with very little provocation. Also those infants tend to somehow pull down to a deep sleep to avoid any further stimulation. And we found that they require a great deal of maternal or caretaker intervention in order to be able to maintain themselves.

We've also found that with early intervention with the mothers we've had a lot of success teaching the mothers how to care for the infants. And when we do this, not only do the infants get the type of stimulation which they require to make good developmental progress but the mothers receive a sense of confidence and an increase in self-esteem that helps them maintain themselves in their programs.

As the children get older we find that with early comprehensive and continual intervention the majority of the 3 and 4 years olds we have followed have achieved levels of social, emotional and intellectual development which place them in the normal range.

These children, however, have received intensive assessment and interventions which are not routinely available. They have been regularly set since birth by pediatricians and psychologists to diagnose and provide intervention for any problems. The have received intervention when necessary from PT's, physical therapists, speech therapists, 0-3 programs and 3-5 programs.

Even with these interventions and the reduction of risk factors in our study, however, 30-40 percent of the cocaine exposed children we follow continue to display problems in the areas especially of language development and/or attention. The language problems do vary considerably in terms of severity from mild articulation problems to more severe auditory and language processing problems.

Most of the children, however, have responded well to interventions by speech pathologists especially when the intervention has been provided at an early age.

Attention difficulties range from mild distractibility to attention deficit disorders with hyperactivity and these problems seem to relate very much self-regulatory problems we noted in our infants.

Children displaying these difficulties have low thresholds for overstimulation and frustration and require consistent structured predictable environments which allow them to develop their own self-regulatory strategies.

Many of these children lose impulse control and/or withdraw from situations which overwhelm their capacities to self-regulate it. These children are particularly likely to respond negatively to changes in routine or environment which occur too rapidly or with no warning, but we found again and again can maintain control if transitions are made gradually and the child is provided with the support and guidance he or she needs.

We've seen 30–40 percent of our children, even with great intervention show problems. However, compared to the children which we have followed, the majority of drug-exposed infants born in this country are at much greater risk for a variety of developmental and/or emotional difficulties.

In addition to the perinatal risk factors to drug-exposed infants, which we discussed earlier in terms of prematurity and poor prenatal care or prenatal nutrition.

Many of the children are placed in postnatal environments which exacerbate rather than alleviate their neurobehavioral problems. Those born severely premature and/or small for gestational age, for example, frequently are placed in neonatal intensive care units which are overstimulating in the extreme and force these infants to shut out stimulation rather than interact with their environments.

Those deserted by their mothers or removed from their mothers' care by protective services, may languish in boarder nurseries with dozens of infants overstimulating each other and too few caretakers to soothe the infants and/or provide them with the experiences necessary to develop self-regulatory abilities.

Those who go to foster homes may be placed with caretakers who haven't been adequately trained to meet the special needs of these children or may be shifted from placement to placement not allowing them to form necessary attachments and forcing them to adapt to a number of different caretaking patterns.

Even those children who remain in the home with the mother, if the mother receives no intervention and continues her drug using lifestyle, may be exposed to many further risks, most commonly including poor postnatal nutrition; poor medical care; chaotic, inconsistent home environments; possible neglect and/or abuse and the potential effects of passive exposure to illicit drugs.

In order to break this cycle of multi-generational substance abuse, we need to address this problem at many levels. We need to offer family therapy for the families aimed at developing healthy, functional relationships among family members many of whom have been the results of multi-generational substance abuse and grown up in pathological homes themselves.

We must provide adequate chemical dependence therapy for the substance abusing parents as well as for substance abusers who aren't yet pregnant. We must provide psychotherapy for the children to allow them to work through emotional problems resulting from the chaotic, inconsistent drug-seeking environment. Finally, we must provide individualized educational programs that meet their unique needs.

To deal adequately with the complex problems of multi-risk children, teachers must be trained to recognize the behavioral cues of the individual child and learn methods for intervening with these children.

Training teachers to provide nurturing, consistent, predictable, well-structured environments to offer greater support and guidance during new or difficult tasks and to ease transitions within the classroom will benefit all children but may be absolutely necessary if those drug-exposed children with self-regulatory problems are to achieve successful learning experiences.

It is very important to note, however, that not every drug-exposed child displays problems and not every child displaying such problems has been drug-exposed. The emphasis, therefore, must be on enabling teachers to meet the needs of every child regardless of the cause of the child's difficulties. To achieve this goal, however, we must insure that teachers receive adequate training and that the number of children in their classrooms is small enough to enable them to individualize education.

In summary then, we cannot paint a stereotypical picture of what so-called crack babies look like and how they will perform in school. The needs and characteristics of infants, toddlers and preschoolers exposed to drugs prenatally vary considerable as the constellation of risk factors to which they are exposed changes.

As these infants get older, a number of them will require special services to foster language development and to develop self-regulatory strategies. Without such assistance the language problems may intensify and behavioral problems of withdrawing and/or acting out may become increasingly rigid.

A major difficulty, however, in obtaining early intervention for the high-risk children in our study, has been the fact that many of them do not show the severity or pervasiveness of delays which make them eligible for federally-mandated services. These children may be left floundering outside the educational system until their abilities have declined enough to receive this funded intervention.

In view of the potential effects which drug abuse during pregnancy has on the long-term developmental outcome of children, as well as the multiple risk factors which so often occur with drug abuse, it is NAPARE's recommendation that all drug-exposed children be classified as high risk and therefore eligible for systematic screening and/or intervention. Thank you.

[The prepared statement of Dr. Dan R. Griffith follows:]

**NAPARE**

NC-6

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May 6, 1991

## CONGRESSIONAL TESTIMONY

Dan R. Griffith, Ph.D.
Developmental Psychologist
National Association for Perinatal Addiction
Research and Education

The primary focus at the National Association for Perinatal Addiction Research and Education (NAPARE) has been the assessment of and intervention with drug-exposed infants/children and their families. Since April, 1986 we have conducted a prospective longitudinal study following the developmental progress of approximately 300 children exposed prenatally to drugs. The majority of these children were exposed to cocaine usually in combination with alcohol, marijuana, and/or cigarettes.

Our experience with this group of mothers and children has demonstrated that drug-exposure is only one of a multitude of risk factors which may impact upon these children and their families.

Direct effects of the life-styles of pregnant chronic substance abusers on the developing fetus may include little or no prenatal care, inadequate prenatal nutrition, poorer general maternal health, and increased incidence of sexually transmitted diseases.

These factors in combination with drug-exposure place the child at increased risk for a variety of problems, the most common of which are intrauterine growth retardation (including stunted brain growth), and prematurity with its sequelae and an increased risk for perinatal morbidity and mortality.

For those infants followed by the NAPARE project many of the risk factors just stated have been reduced. The women enrolled in the project received prenatal care and chemical dependence therapy which beginning in the first trimester of pregnancy, served to eliminate or reduce their drug use during pregnancy. The improved pregnancy outcomes of these women point out the importance of early identification of and treatment of pregnant substance abusers: for those women who were able to stop using cocaine during the first trimester of pregnancy the rate of prematurity was only 17% as compared to 31% for those who continued to use and the incidence of low birthweight babies was 0% compared to 25% for those using throughout pregnancy.

The cessation of cocaine use during the first trimester, however, did not improve the neurobehavioral outcome of the newborns. It is true, however, that the vast majority of the infants in our study were exposed to heavy amounts of cocaine during mothers use even if that use only lasted through the first trimester. Those exposed to cocaine in the first trimester only were equally deficient as compared to those exposed all three trimesters in terms of state regulation, motor control, and interactive capabilities. This speaking to the need for drug-use prevention programs and the identification of and intervention with female substance abusers of child-bearing age prior to pregnancy.

The heavily exposed newborn infants we have seen can best be described as low threshold infants. These infants often move from sleeping states to screaming with minimal amounts of stimulation or pull into sleep states to avoid stimulation completely. Many need to be wrapped tightly in their blankets to control disorganized, jerky motor movements. Most of them have difficulty responding to the complexities of the human face. These infants require consistent, predictable, low-stimulus environments with caretakers who can spend quality time with the infants, providing stimulation appropriate for the infants and helping the infants to develop self-regulatory abilities. We have found that when the mothers can be trained to interact with their infants in sensitive, appropriate ways the infants receive the level and quality of stimulation which they require to progress developmentally, and the mothers form a positive bond towards the infant while building a stronger sense of self-esteem.

As the cocaine-exposed children in our study get older we have seen that early, comprehensive, continual intervention has enabled the majority of the 3 and 4 year olds we are following to achieve levels of social, emotional, and intellectual development which place them in the normal range. These children have, however, received intensive assessment and interventions which are not routinely available. They have been regularly assessed since birth by pediatricians and psychologists to diagnose and provide intervention for any problem. They have received intervention when necessary from physical therapists, speech therapists, zero to three programs, and 3-5 programs. Even with these interventions and reduction of risk factors, however, 30 to 40% of the cocaine-exposed children we follow have continued through ages 2, 3, and now 4 years do display problems in language development and/or attention. The language problems range from articulation difficulties to severe language processing problems Most of the children have responded well to interventions by speech pathologists. The attention difficulties range from mild distractibility to attention deficit disorders with hyperactivity. The attentional problems appear to be related to the types of self-regulatory problems noted in our infants. Children displaying these difficulties have low thresholds for overstimulation and frustration and require consistent, structured, predictable environments which will allow them to develop self-regulatory strategies. Many of the children with attentional problems lose impulse control or withdraw from situations which overwhelm their capacities to self-regulate. These children are particularly likely to respond negatively to changes in routine or environment which occur too rapidly or with no warning, but can maintain control if transitions are made gradually and the child is provided with additional support and guidance.

Compared to the children which NAPARE has followed, the majority of drug-exposed infants born in this country are at greater risk for a variety of developmental and/or emotional difficulties. In addition to the perinatal risk factors for drug-exposed infants, many of them are placed in postnatal environments which exacerbate rather than alleviate their neurobehavioral problems. Those born severely premature and/or small for gestational age are placed in Neonatal Intensive Care Units which are overstimulating in the extreme. Those deserted by their mothers or removed from their mothers' care by protective services may languish in boarder nurseries with dozens of infants overstimulating each other and too few caretakers to soothe the infants and provide them with the experiences necessary to develop self-regulatory abilities. Those who go to foster homes may be placed with caretakers who haven't been adequately trained to meet the special needs of these children, and/or the infants may be shifted from placement to placement not allowing them to form necessary attachments and forcing them to adapt to different caretaking patterns.

Those children who remain in the home of the mothers who have received no intervention and continue the drug using life-style may be exposed to many further risks including poor nutrition and medical care; chaotic; inconsistent home environment; possible neglect and/or abuse; and the potential effects of passive exposure to illicit drugs.

To save the child and break the cycle of multigenerational substance abuse so common among the families we work with we must address their problems at many levels. At the family level we must offer family therapy aimed at developing healthy, functional relationships among family members. We must provide adequate chemical dependence therapy for the substance abusing parents. We must provide psychotherapy for the children to allow them to work through emotional problems resulting from the chaotic, inconsistent drug-seeking environment. Finally, every child must be provided with individualized educational program that meet their unique needs.

To deal adequately with the complex problems of multi-risk children, teachers must be trained to recognize the behavioral cues of the individual child and must learn the methods for intervening with these children. Most of the children we have studied who exhibit self-regulatory problems provide early warning signs such as increased rates and randomness of activities which tip the caretakers off that the children are losing impulse control. Intervening at the first signs of self-regulation difficulties by engaging the children in structured, focused activities can avoid more severe problem behaviors which frustrate the teacher and child while disrupting the educational environment of the whole classroom. Training teachers to provide nurturing, consistent, predictable, well-structured environments; to offer greater support and guidance during new or difficult tasks; and to ease transitions within the classroom will benefit all children but may be absolutely necessary for those drug exposed children with self-regulatory problems to achieve successful learning experiences. It is important to note that not every drug-exposed child displays problems and not every child displaying the problems outlined here has been drug-exposed. The emphasis therefore must be on enabling teachers to meet the needs of every child regardless of the cause of the child's difficulties. To achieve this goal, however, we must ensure that teachers receive adequate training and that the numbers of children in their classrooms are small enough to enable them to individualize education.

In summary, we cannot paint a stereotypical picture of what so-called "crack-babies" look like and how they will perform when they reach school. The needs and characteristics of infants, toddlers, and preschoolers exposed to drugs prenatally vary considerably as the constellation of risk factors to which they are exposed changes. As these infants get older a number of them require special services to foster language development and to develop self-regulatory strategies. Without such assistance the language problems may intensify and the behavioral problems of withdrawing and/or acting out may become increasingly rigid. A major difficulty, however, in obtaining early intervention for the high risk children in our study has been the fact that many of them do not show the severity of or pervasiveness of delays which make them eligible for federally mandated services. These children may be left floundering outside the educational system until their abilities have declined enough to receive funded intervention.

In view of the potential effects which drug abuse during pregnancy may have on the long-term developmental outcome of children and the multiple risk factors which so often occur at the same time, it is NAPARE's recommendation that all drug-exposed children be classified as high-risk and therefore be eligible for systematic screening and/or intervention.

Chairman OWENS. Thank you.

Dr. William Scarbrough.

Dr. SCARBROUGH. On behalf of the National Center for Children in Poverty I want to thank you Chairman Owens and Congressman Payne for inviting me to testify this afternoon.

I apologize, or may have to apologize in advance, for dashing out of here around 6, 6:30. I have a class that I teach at 7 o'clock on Monday nights at Columbia University with the other hat that I wear as Assistant Clinical Professor of the School of Public Health and the School of Social Work. But I am, as I said, very pleased to be here and I will try to hang out as long as I can.

I am also accompanied this afternoon by Mr. Bob Fulton, who is the former Secretary of Social Services for the State of Oklahoma and is also the senior policy advisor to the National Center for Children in Poverty at Columbia University.

The Center has a strong interest in promoting the healthy growth and development of poor children. In an effort to increase public understanding of the sheer magnitude of the problem of child poverty, the changing demographics, social and economic characteristics of poor families with young children and the increased health and development risks some poor children face, we have published two major reports over the last year.

First, last year, and appreciate the reference to the report, we published a report entitled, "Five Million Children: A Statistical Profile of Our Poorest Young Citizens." This report examines the demographic, social and economic characteristics of poor children and their families, and it summarizes the comparative health and development risks poor children face.

In summary, it shows that poor children, compared to low- and middle-income children, are disproportionately minority, and more likely to be living with single mothers who are under-educated and under-employed. We found that these children are more likely to suffer from prematurity, low birthweight, poor nutrition, accidental injury, child abuse and neglect, and more recently from AIDS and prenatal drug exposure.

We magnified our focus on the health risks faced by infants and children living in poor families in our 1991 report released just a month or two ago entitled, "Alive and Well? A Research and Policy Review of Health Programs for Poor Young Children." This report examines in detail indisputable evidence linking poverty to poor birth outcomes, increased illness and increased mortality among infants and children in low-income families.

The report states that poor children suffer disproportionately from low birthweight, HIV infection, asthma, dental decay, measles, nutritional problems, lead poisoning, unintentional injuries and maltreatment.

Both of these reports reach a similar conclusion, that major improvements in the growth and development of infants and children living in disadvantaged families will only be achieved through substantial commitments at all levels of government to 1) reduce poverty rates, 2) enforce broad, preventative public health measures, 3) reduce unwanted pregnancies, and 4) expand the number of health care organizations willing and able to provide the range of services that poor families need.

One potentially important, yet seriously underutilized, government commitment to improving the lives of poor children under the age of six, is Public Law 99-457, The Individuals with Disabilities Act. Specifically, Part B, Section 619 and Part H, Section 672 are directly relevant to disadvantaged infants and toddlers who are at risk of experiencing substantial developmental delays if early intervention services are not provided.

The problems of young children who are physically or mentally disabled, and those at risk of developmental problems, are usually described and categorized in terms of three general groupings: established conditions, biological risk, and environmental risk. Established conditions refers to things such as Down's Syndrome, spina bifida, cerebral palsy and other diagnosed conditions.

Biologic risk factors include prematurity, low birthweight, neonatal asphyxia, fetal alcohol syndrome, intracranial hemorrhage and a host of other problems. Environmental risk facts include extreme poverty, which can bring with it many other problems such as late or no prenatal care, lack of permanent housing, consistently poor nutrition, abuse or neglect, and family dysfunction.

Perfect agreement on what constitutes developmental risk is not possible at this time and I haven't seen a decent agreement on that definition to this point. The research literature examining multiple risk factors across these risk categories and estimates of the numbers of infants and toddlers affected nationally are virtually nonexistent.

The risk categories outlined above and the risk factors themselves are not mutually exclusive. And I think Dr. Griffith had made a point of that. It is important to keep in mind that a child's development is influenced by multiple interacting factors.

The primary reason multi-risk factor research has been so limited is there's currently no single data base that adequately measures the presence and severity of handicapping conditions, biologic risk characteristics of the mother and the child, environmental risk characteristics and measure of cognitive, physical, speech and language, and psychosocial development amongst infants and toddlers.

National data bases such as the current population survey, the national health interview survey, the survey of income and program participation and longitudinal survey of youth are examples of data bases necessary to build multi-risk models for a population estimation and program effectiveness research.

None of these data bases at present allows us to build a sufficiently complete risk model of developmental problems for infants and toddlers. Further, the samples for all these data bases are not sufficiently large to allow stable estimation of the numbers of children at-risk at sub-national levels such as the State level or local levels, arguably, the place where this information is most in need.

Another reason multi-risk factor research has been so limited to date is the fact that risk factors affecting child development are dynamic. In order to assess the effect of risk factors on developmental outcomes, both must be measured periodically for the same group of children; in other words, longitudinally. Currently only one data base has been developed to do just that at the national level, that is the national longitudinal survey of youth.

Because of this state of affairs there are no reliable national estimates of the numbers of infants and toddlers at-risk of developmental disorders due to established conditions and biological and environmental risk factors.

In order to shed a little light on this subject, I synthesize for the record from some of our work and the work of others, estimates of these risk factors and how many children under the age of 3 would be affected. Caution is suggested, however, in interpreting the numbers. It is inappropriate, given the interrelations of many of these risk factors such as poverty, low maternal education, lack of prenatal care, lack of stable and adequate housing, to simply add the numbers across these various factors and arrive at a population at-risk.

As such, by combining extreme poverty, as an example, combining extreme poverty, in other words, families living in—children living in families with incomes below 50 percent of the poverty line. By the way, for a family of four in this country in 1990 that would be approximately $6,500. If you combine extreme poverty with maternal age younger than 20, age at first birth and lack of health insurance as a proxy for disadvantage, you end up finding that there are about 100,000 children under the age of 3 that fall into particular constellation of risk factors.

There is a serious lack of information regarding the number of infants and toddlers who, because of established conditions, biological and environment factors, experience or are at-risk of developmental problems. Only with improvements in our current data systems can we expect to arrive at estimates of the numbers and characteristics of infants and toddlers at-risk of developmental problems.

And only with good estimates of those at-risk can we confidentially allocate our scarce resources.

But the trade-off of not investing our scarce resources now will be the need to invest much larger sums of money and other resources later to serve those ignored children. Thank you very much.

[The prepared statement of Dr. William H. Scarbrough follows:]

No. 7

Columbia University School of Public Health
**NATIONAL CENTER FOR CHILDREN IN POVERTY**

Testimony before the U.S. House of Representatives Committee on Education and Labor, Subcommittee on Select Education: Hearing on the "Reauthorization of the Early Intervention Program (Part H) and the Preschool Program (Part B, Section 619) of the Individuals with Disabilities Education Act (P.L. 99-457)"

William H. Scarbrough, Ph.D.
Associate Director for Research,
National Center for Children in Poverty
and Assistant Clinical Professor of Public Health
Columbia University School of Public Health

*May 6, 1991*

Chairman Owens and members of the Subcommittee, my name is William Scarbrough. I am an Assistant Clinical Professor of Public Health and Associate Director for Research at the National Center for Children in Poverty, Columbia University in New York. I am pleased to provide testimony this afternoon on an issue of great importance to the future of this country: the healthy growth and development of young children, particularly poor children.

## Introduction

The National Center for Children in Poverty was established in 1989 at Columbia University with support from the Ford Foundation and the Carnegie Corporation of New York. The Center's goal is to strengthen policies and programs for poor children under age six and their families. To achieve this goal the Center collects, analyzes, synthesizes, and actively disseminates information about poor children and families, and about public policies and programs designed to address their needs. The Center is also initiating projects through which we will assist state and local agencies directly to plan and implement improved policies and promising program approaches in the fields of maternal and child health, child care, and service integration.

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The Center has a strong interest in promoting the healthy growth and development of poor children. In an effort to increase public understanding of the sheer magnitude of the problem of child poverty, the changing demographic, social and economic characteristics of poor families with young children, and the increased health and development risks some poor children face, we have published two major reports over the last year.

First, in 1990, we published a report entitled *Five Million Children: A Statistical Profile of Our Poorest Young Citizens*. This report examines the demographic, social and economic characteristics of poor children and their families, and it summarizes the comparative health and development risks poor children face. In summary, it shows that poor children, compared to low- and middle-income children, are disproportionately minority, and living with single mothers who are under-educated and under-employed. As a result, the children are more likely to suffer from prematurity and low birthweight, poor nutrition, accidental injury, child abuse and neglect, and more recently, from AIDS and prenatal drug exposure. We found that these problems are more prevalent among families who lack adequate resources—that is, the families of these children are less likely to be able, for example, to arrange and pay for quality child care, to provide a safe, nurturing and intellectually stimulating environment, and to find a convenient and affordable source of primary health care.

Second, we magnified our focus on the health risks faced by infants and children living in poor families in our 1991 report entitled *Alive and Well? A Research and Policy Review of Health Programs for Poor Young Children*. This report examines, in detail, indisputable evidence linking poverty to poor birth outcomes, increased illness, and increased mortality among infants and children in low-income families. The report states that poor children suffer disproportionately from low birthweight, HIV infection, asthma, dental decay, measles, nutritional problems, lead poisoning, unintentional injuries, and maltreatment.

Both of these reports reach a similar conclusion—that major improvements in the growth and development of infants and children living in disadvantaged families will only be achieved through substantial commitments at all levels of government to (1) reduce poverty rates, (2) enforce broad, preventive public health measures, (3) reduce unwanted pregnancies, and (4) expand the number of health care organizations willing and able to provide the range of services that poor families need.

## Improving Poor Children's Chances for Healthy Development: The Potential of P.L. 99-457, The Individuals with Disabilities Act

One potentially important, yet seriously underutilized, government commitment to improving the lives of poor children between the ages of birth and three years is Public Law 99-457, The Individuals with Disabilities Act (formerly the Education of the Handicapped Act). Specifically, Part H, Section 672, Subsection 1 of the law covers all handicapped infants and toddlers (from birth up to age three) who need early intervention services because they (1) are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures, in the areas of cognitive development, physical development, language and speech development, psychosocial development, or self-help skills; or (2) have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. The law goes on to state that infants and toddlers who are at risk of experiencing substantial developmental delays if early intervention services are not provided can also be included, at state discretion. To date, only six states have attempted to include infants and toddlers at risk of developmental problems. It is this last sentence in the subsection, as it relates to disadvantaged infants and toddlers, that is addressed in the following pages.

## Children At Risk of Developmental Disorders: Who Are They and How Many of Them Are at Risk?

The problems of young children who are physically or mentally disabled, and those at risk of developmental problems are usually described in terms of three general categories: established conditions, biological risk, and environmental risk (Tjossem, 1976). Established conditions refers to Down syndrome, spina bifida, cerebral palsy, and other diagnosed conditions. Biologic risk factors include prematurity, low birthweight, neonatal asphyxia, fetal alcohol syndrome, intracrannial hemorrhage and a host of other problems. Environmental risk factors include extreme poverty, which can bring with it other problems such as late or no prenatal care, lack of permanent housing, consistently poor nutrition, abuse or neglect, and family dysfunction.

Perfect agreement on what constitutes developmental risk is not possible at this time. While there exists a large body of research literature that illustrates the relationship between many established and biologic risks and developmental problems (Shonkoff and Marshall, 1990), there is relatively little research clearly showing the relationship between environmental risks, such as extreme poverty or poor family functioning, and poor child development. Further, the research literature examining multiple risk factors across the risk categories and estimates of the numbers of infants and toddlers affected nationally is virtually nonexistent.

The risk categories outlined above (and the risk factors themselves) are not mutually exclusive. It is important to keep in mind that a child's development is influenced by multiple, interacting factors. For example, although children born prematurely may be enrolled in special education programs at a higher rate than children born full-term, these children usually experience a number of other risk factors besides prematurity that play a significant role in their development. Those factors could be biological, such as neonatal seizures, chronic lung disease, sensory disorders, or persistent feeding problems. Or they could be environmental, such as early and prolonged inattentive caregiving, absence of family support, or severely adverse economic conditions leading to problems in accessing or obtaining necessary and sufficient conditions for healthy growth and development. Or they could be both biological and environmental (NCCIP, 1989).

The primary reason multi-risk factor research has been so limited is that there is currently no single database that adequately measures the presence and severity of handicapping conditions, biologic risk characteristics of the mother and the child, environmental risk characteristics, and measures of cognitive, physical, speech and language, and psychosocial development among infants and toddlers. Examples of national databases that collect health, economic, and demographic characteristics, and child development outcomes include:

> Current Population Survey
> (cross-sectional; predominantly economic and demographic characteristics, few health measures, no child development measures);
>
> National Health Interview Survey
> (cross-sectional; predominantly health measures, some economic and and demographic characteristics, no child development measures);

Survey of Income and Program Participation
(longitudinal; predominantly program participation,
economic and demographic characteristics, some health
measures, no child development measures); and

National Longitudinal Survey of Youth [NLSY]
(longitudinal; predominantly child development outcome measures,
and economic and demographic characteristics, few health measures).

None of these databases, at present, allows us to build a sufficiently complete risk model of developmental problems for infants and toddlers. Further, the samples for all of these databases are not sufficiently large to allow stable estimation of the numbers of children at risk at subnational levels (such as the state or local level—policymakers and program operators at these levels are most in need of this information).

Another reason multi-risk factor research has been so limited to date is that the risk factors affecting child development are dynamic. In order to assess the effect of risk factors on developmental outcomes, both must be measured periodically for the same group of children. Currently only one database has been designed to do just that at the national level—the NLSY. The problems with the NLSY, as noted above, are its lack of a complete list of biologic risk measures and insufficient sample size to allow for stable subnational estimation.

Because of this state of affairs, there are no reliable national estimates of the numbers of infants and toddlers at risk of developmental disorders due to established conditions, and biologic, and environmental risk factors. In an attempt to provide the Committee with estimates of the numbers of infants and toddlers potentially at risk of developmental problems, I present below ten selected risk factors and estimates of the numbers of infants and toddlers suffering from those risks nationally. Caution is suggested in interpreting these numbers. It is inapproriate, given the interrelations of many of these risk factors (such as poverty, low maternal education, lack of prenatal care, and lack of stable and adequate housing), to simply add the estimates together to arrive at the population "at risk". When the factors overlap, the numbers of children at risk are reduced. Where possible, estimates have been provided for those suffering from multiple risk factors. The estimates are based on information found in the research literature and the analytic work we conducted in relation to *Five Million Children* and *Alive and Well?*

Established Conditions **(15,000 - 80,000)**

1. Approximately 1 to 2 percent of all infants are born with discernable disabling conditions (that is, established risks such as Down syndrome). This translates to between roughly 15,000 and 80,000 infants annually. By the time children enter school, 10-12 percent are found to have some degree of disability (ranging from physical and mental disabilities to speech and language development delays). This translates to between 350,000 and 400,000 children (Blackman, 1986).

Biologic and Environmental Risks

2. Economic Deprivation **(1.2 - 2.5 million)**

There is considerable debate about the exact processes that translate acute economic deprivation into developmental risk for children, but experts agree that economic deprivation represents a challenge to the coping resources of individuals, families, and communities (Fisher and Cunningham, 1983).

Poverty affects the health, education and welfare of mothers which, in turn, can have an effect on premature births, low birthweight, malnutrition and the welfare of infants and toddlers. During late 1970s and throughout the 1980s, economic deprivation was most common among families with young children. In 1989, the poverty rate among infants and toddlers (children under age three) reached almost 25 percent—one out of every four children—or about 2.5 million children. Since 1987, the poverty rate has remained fairly stable.

However, not all poor infants and toddlers experience developmental problems. Those most at risk (because of acute economic deprivation) are the approximately 1.2 million children under age three whose family incomes are below 50 percent of the poverty line. Since 1986, the number of children under age three whose family incomes were below 50 percent of the poverty line has grown by 12 percent (National Center for Children in Poverty, 1990).

3. Maternal Age Less Than 15 Years **(31,000)**

According to the Census Bureau, there were approximately 8 million women between the ages of 10 and 14 in the US in 1989. The birth rate for women in this age group was 1.3 per 1000 women. If the number of women in this age group and the birth rate remained constant over a three year period, the total number of infants and toddlers born to young mothers would be roughly 31,000. The birth rate for these women has grown by nearly 20 perent since 1980(U.S. Department of Commerce, 1990).

4. Maternal Education Less Than High School **(2.4 million)**

During the late 1980s, one out of every five births in the US was to a mother who had not completed high school—translating to roughly 800,000 infants per year—or 2.4 million children under three. This number represents a 15 percent increase over the early 1980s (U.S. Department of Commerce, 1990).

Maternal Education Less Than High School and Poverty **(1.1 million)**

If risk is defined as living below the poverty line and maternal education being less than high school, the number of children under three at risk would be about 1.1 million. Since 1980, the number of children under three living in poor families with a mother who did not graduate from high school increased 22 percent (National Center for Children in Poverty, 1990).

5. Late or No Prenatal Care **(220,000)**

According to vital statistics from the National Center for Health Statistics (NCHS, 1989) and a study conducted at the Alan Guttmacher Institute (AGI, 1989), about 6 percent of all infants born in the US are born to women who received late (i.e., after the second trimester) or no prenatal care. This translates to roughly 220,000 infants. Throughout the 1980s, the proportion of women initiating care in the third trimester or receiving no care at all increased 5 to 6 percent.

6. Maternal Substance Abuse **(39,000 - 1.2 million)**

Hospital estimates of drug-exposed newborns range from as low as 1-2 percent to as high as 42 percent depending upon the substance abused and the hospital studied (Zuckerman, et. al., 1989). If these percentages were applied to all newborns in any given year, the number would range between 39,000 and 1.2 million. The National Institute on Drug Abuse has estimated that in 1988 about 5 million women of childbearing age used illicit drugs (USGAO, 1990). This represents a 20 percent increase over the early 1980s.

7. Low Birthweight **(267,000 - 350,000)**

According to vital statistics from NCHS (1988), approximately 7 percent of all infants born in the US are low birthweight (under 2500 grams)—this translates to approximately 267,000 infants. Since 1984, the proportion of babies born at low birthweight increased slightly (2 percent). The Institute of Medicine (1985) found that low income is clearly associated with increased risk of low birthweight.

8. Lead Exposure **(1.5 million)**

More than 1.5 million children under the age of three suffer from elevated lead levels. Higher levels of lead present in the blood are known to cause serious brain damage. Health experts agree that even low levels of lead exposure can cause decreased intelligence, short-term memory loss and underachievement in school. Among very young children, low levels of exposure can have a long-term effect on a child's ability to learn (Environmental Defense Fund, 1990).

9. Malnutrition/Hunger **(330,000 - 390,000)**

Between 1972 and 1988, 9 to 11 percent of infants and young children consistently fell below the NCHS growth chart's fifth percentile for height for age and 3-4 percent were consistently below the fifth percentile for weight for height (HHS, 1989). If these percentages were applied to only infants and toddlers, this would translate to between roughly 330,000 and 390,000 children nationally.

10. Homeless/Precariously Housed **(27,000 - 78,000)**

The US General Accounting Office reports that approximately 68,000 children and youths aged 16 years and younger were members of families who were literally homeless and another 186,000 were precariously housed—doubled up in shared housing. Among the children whose ages were reported, about 40 percent were aged three years and younger (27,000-78,000).

## Closing Remarks

There is a serious lack of information regarding the number of infants and toddlers who, because of established conditions, biological, and environmental factors, experience or are at risk of developmental problems. Few research studies exist that have examined the effects of multiple risk factors over time, and those that have are limited to specific subnational populations. With already constrained state budgets, and without better estimates of these populations, new services are not likely to be created.

In order to help improve effective distribution of limited resources to improve infant and toddler development, a systematic examination of national databases that collect child developmental outcomes (such as the NLSY) should be conducted to determine if the data collection procedures could be augmented to include data regarding established conditions, biologic, and environmental risk factors related to developmental problems. Further, the samples of those databases should be examined to determine the relative costs and benefits of increasing the sample size to allow for stable subnational estimation. Only with improvements in our current data systems can we expect to arrive at reasonable estimates of the numbers and characteristics of infants and toddlers at risk of developmental problems. And only with good estimates of those at risk can we confidently allocate scarce resources.

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Chairman **Owens**. Thank you.

Bernard Charles.

Mr. **Charles**. Thank you, Mr. Chairman, and the members, Congressman Payne. My name is Bernard Charles, I am Senior Vice President of the Quality Education for Minorities Network, a nonprofit organization in Washington, DC, established in July 1990, and dedicated to improving education of minorities throughout the Nation.

The Network is a focal point for the implementation of strategies to help realize the vision and goals set forth in the report, "Education That Works: An Action Plan For The Education of Minorities." The report was issued in January 1990 by the MIT-based Quality Education for Minorities Project, following more than two years of travel, visiting nine major cities from San Juan, Puerto Rico to Anchorage, Alaska, exploring effective programs and strategies to improve the education of minority children, youth and adults.

The focus of this hearing on infants, toddlers and preschoolers at-risk could not come at a more appropriate time. As the Nation seems preoccupied with international issues, dominated by our continued involvement in the Gulf War, peace efforts in the Middle East, huge budget deficits and a declining economy, less emphasis is being placed on domestic policy issues. I want to compliment the subcommittee for bringing these hearings to the community most affected by this neglect.

As is so often the case, those who are powerless in our society, primarily the poor and young children, are the first to suffer from this lack of attention. This is evidenced by the inadequacy of funding and the under-funding of the various nutritional and health programs such as Head Start and Women, Infants and Children, WIC as it's commonly known. We need a strong voice for those without a political voice in the ensuing national debate on setting the education agenda for the remainder of the decade and into the twenty-first century.

While recognizing that there are many children at-risk in our nation because of changing family patterns, inadequate access to health care, high unemployment, a limited supply of affordable housing, and poor educational opportunities, recommendations and strategies for addressing the problems of these children must have broad application for all children.

My comments this evening, however, will focus on minority children who, in addition to the factors listed above, are adversely affected by persistent racism and who are disproportionately underserved by our nation's education, health and social service systems and who are most at-risk in our society.

According to the Center for Disease Control in Atlanta, a primary concern should be the increasing to near epidemic proportion of young children, particularly in our inner cities, who are victims of measles, rubella, whooping cough and other contagious diseases. The Center reports more than 26,500 cases of measles were reported nationwide last year, up from 18,193 confirmed cases in 1989.

They found that more than half of the cases occurred among unvaccinated preschool age children. These children are unduly exposed either because eligible parents are unaware of the existence of free immunization programs, or parents are unable to afford the cost of having their children vaccinated because of inadequate health insurance.

These services, when available, are often in areas too distant by public transportation and frequently are open at a time of day too inconvenient for families with multiple responsibilities. Clearly, this disease and others are preventable in a nation as rich as ours.

What is missing is the will and commitment to take appropriate steps to eradicate any of these structural conditions and assure that no child is without adequate care to prevent these diseases from recurring. Though most children meet State requirements to be vaccinated against measles and other childhood disease before entering school, there is no universal requirement for preschool age children to be immunized. The Center for Disease Control recommends that this situation be corrected now.

The QEM report, and many others, conclude that in order to address prevention and intervention programs that seek to target young children ages 0–6, strategies must center on the family, whether that be a traditional two parent, single parent, foster care or extended family.

Parents are their children's first teacher and are ultimately those most responsible for their education.

Children learn about treating others by the way they are treated within the family and community. Family teaching is the basis of socialization, producing the sense of safety for the child. Parents can make a difference one way or another in the way children view themselves as contributing members of the larger society.

The question is often asked, how early should the intervention take place? I would argue at the prenatal stage or as soon as the mother-to-be becomes aware that she is pregnant. If we reflect for a moment, it is at that point that actions begin to determine what kind of life the child is to have. Decisions as to where one is to live and what kind of education the child is to have are all limited by economic factors, social support networks, and human resources available to the individuals involved.

Women or parents from less advantaged or poverty backgrounds often view their options as being limited by circumstances beyond their control because many decisions are made for them by others within and outside the social welfare system.

Admittedly, children and families living in the poorest neighborhoods with the fewest basic support services face the greatest obstacles in moving out of poverty and improving the quality of their lives.

Increasing the availability of health and human services through cooperative arrangements with day care centers, public schools, churches and other community-based organizations would go a long way toward ameliorating their life circumstances.

But there are decisions that women can control to give their child the opportunity to fulfill his or her promise for a full and productive life, namely, abstaining from abusive substances such as smoking, alcohol, various drugs, poor nutrition and increasing the frequency of doctor visits. Each of these factors, or any combination thereof, contributes to low birthweight, premature births, fetal drug exposure and other major medical complications which frequently lead to physical handicaps, mental retardation and learning disabilities.

According to a recent report of the National Center for Children in Poverty, in 1987 there were 5 million children under the age of 6 who lived in families below the poverty line. 2.1 million (42 percent) were white; 1.6 million (32 percent) were Black; 1 million (21 percent) were Hispanic; and a quarter of a million (5 percent) were from other racial or ethnic minorities predominantly Asian and Native Americans.

The report also notes that 48 percent of young Black children, 42 percent of young Hispanic children and 20 percent of young children from other minority groups were poor. In sharp contrast, only 13 percent of young white children were poor.

These figures, as devastating as they appear, can only worsen unless dramatic intervention programs are initiated and fully-funded at the national, State and local levels. I will return to this issue later on in my testimony.

By now we are all aware of the changing demographics that predict by the year 2010, 38 percent of all children will be minority and some estimate that by the year 2040, just 50 years from now, the majority of the Nation's population will be non-white. The fundamental component of this transformation is the increasing minority birth rate and the decline in the white birth rate, especially that of the white middle class since the mid sixties. The implication of this data for our nation's future technological competitiveness in the increasingly global economy cannot be underestimated.

Already minorities constitute the majority of school enrollments in 22 of 25 of the Nation's largest cities, which includes New York, and 60 of the 75 largest urban school districts. Furthermore, it is projected that by the year 2010 California, Texas, Florida and New York will join Mississippi and New Mexico in having minority students in the majority in their school systems.

The quality of education for minority students has already triggered a healthy debate among educators, the business community, State governments and the philanthropic sector as well as the forging of new partnerships around improving the quality of our future work force.

The focus of this hearing addresses Goal One of the six major goals in our report, "Education That Works: An Action Plan for the Education of Minorities" in which we challenge the President, the governors and the Nation to ensure that minority students start school prepared to learn.

The demographic realities make this an urgent issue. The QEM report made this the first goal because it is clear that to affect the way minority children are educated at all points along the educational pipeline, every effort must be made to ensure that they enter school each year with the foundation for intellectual curiosity and healthy development essential to academic success as they move along the education continuum.

This goal also coincides with the first of six national education goals adopted by President Bush and the Nation's governors that by the year 2000 all children in America will start school ready to learn. We believe, that because we shared our draft report with the

President's Domestic Policy Office and the National Governors Association, QEM influenced their decision in this regard.

It should be noted, however, that in the recently released report, "America 2000: An Education Strategy" by the President and Secretary of Education, Lamar Alexander, this goal is ignored. Regardless of the reason for this Commission, Goal One is critical to the achievement of each of the remaining goals, whether QEM's goals or the national education goals.

Therefore, any strategy must respond to the first goal. We must stiffen our resolve to make this first and crucial step a major part of our advocacy for children and especially minority children whose issues are not addressed in this latest report from the administration.

We believe that this goal can be achieved if the Nation were to increase access to quality pre- and postnatal health care, increase participation in child nutrition programs, ensure that every preschooler has access to quality day care and early childhood education, enable all parents to better assume their roles as first teachers of their children.

To make this goal a reality we recommend that Federal, State and local governments increase participation in the women, infants and children WIC program so that by 1995 all the eligible participants are provided support, double the participation in child nutrition programs, increase Federal funding and State funding for child care programs to cover a 100 percent participation rate of preschoolers with mothers on welfare or for working mothers whose income is 150 percent of the poverty line, increase enrollment in Head Start incrementally over the next five years to cover 100 percent of the eligible population by 1995, invest in new approaches to easing and strengthening the home-to-school transition.

In our site visits we found numerous examples of successful intervention programs that work with minority children across the education spectrum. For purposes of this hearing, I will cite only a few. AVANCE, a parent education program in San Antonio, Texas trains parents to assume their role as the primary teachers of their children, it's an early intervention.

The Saturday Science Academy at the University of California at Irvine requires Black parents to attend half the sessions with their children. The California Quality Education Project with 100,000 students in 16 school districts across the State asks parents to pledge that they will set aside study time at home, get their children to school on time, read to the children every day, attend back-to-school nights and attend parent-teacher conferences. If they can't read to their children, listen to their children.

A critical element in those successful intervention programs and in others was that most were conceived, developed and implemented outside the local school system.

To the credit of some of these systems, however, once the programs demonstrated their capacity to impact the targeted groups, or received broad community or political support, they were quickly incorporated into the regular school curriculum. Clearly, there are lessons to be learned from these community-based efforts.

Mr. Chairman, I urge you and your fellow committee members to include language within the reauthorization legislation under consideration this evening to allow these local initiatives to become the core of efforts designed to improve the quality of life in their communities.

Finally, minority community leaders and those of us who have achieved economic and educational success must take responsibility for our own people. Our energy, ideas and money must return to the communities and to our children. No one can, or should, do it for us. Thank you.

[The prepared statement of Bernard Charles follows:]

No. 8

# TESTIMONY
# OF
# BERNARD L. CHARLES
# SENIOR VICE PRESIDENT
# QUALITY EDUCATION FOR MINORITIES NETWORK
# BEFORE THE
# SUBCOMMITTEE ON SELECT EDUCATION OF THE COMMITTEE ON EDUCATION AND LABOR
# U.S. HOUSE OF REPRESENTATIVES
# CLARA BARTON HIGH SCHOOL
# BROOKLYN, NEW YORK
# MAY 6, 1991

Mr. Chairman, members of the Subcommittee on Select Education, my name is Bernard L. Charles. I am Senior Vice-President of the Quality Education for Minorities Network, a non-profit organization in Washington, D.C. established in July 1990 and dedicated to improving education for minorities throughout the nation. The Network is a focal point for the implementation of strategies to help realize the vision and goals set forth in the report: **Education That Works: An Action Plan For The Education of Minorities**. The report was issued in January 1990 by the MIT-based Quality Education for Minorities Project, following more than two years of travel visiting nine major cities from San Juan, Puerto Rico to Anchorage, Alaska exploring effective programs and strategies to improve the education of minority children, youth and adults.

I appreciate the opportunity to comment on the reauthorization of the EARLY INTERVENTION PROGRAM (Part 14) and the Pre-school program (Part B, Section 619) of the INDIVIDUALS WITH DISABILITIES EDUCATION ACT (Formerly EHA).

The focus of this hearing on infants, toddlers, and preschoolers at risk could not come at a more appropriate time. As the nation seems preoccupied with international issues, dominated by our continued involvement in the Gulf War, peace efforts in the Middle East, huge budget deficits and a declining economy, less emphasis is being placed on domestic policy issues. I want to compliment the subcommittee for bringing these hearings to the communities most affected by this neglect.

As is so often the case, those who are powerless in our society, primarily the poor and young children, are the first to suffer from this lack of attention. This is evidenced by the inadequacy and under-funding of the various nutritional and health programs such as Head Start and Women, Infants and Children (WIC). We need a strong voice for those without a political voice in the ensuing national debate on setting the education agenda for the remainder of the decade and into the twenty-first century.

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Already minorities constitute the majority of school enrollments in 22 of 25 of the nation's largest cities, which includes New York, and 60 of the 75 largest urban school districts. Furthermore, it is projected that, by the year 2010, California, Texas, Florida, and New York will join Mississippi and New Mexico in having minority students in the majority in their school systems. The quality of education for minority students has already triggered a healthy debate among educators, the business community, state governments, and the philanthropic sector as well as the forging of new partnerships around improving the quality of our future workforce

The focus of this hearing also addresses Goal One of the six major goals in our report: **Education That Works: An Action Plan for the Education of Minorities** in which we challenge the President, the governors and the nation to:

**ENSURE THAT MINORITY STUDENTS START SCHOOL PREPARED TO LEARN.**

The demographic realities make this an urgent issue. The QEM Report made this the first goal because it is clear that to affect the way minority children are educated at all points along the educational pipeline, every effort must be made to ensure that they enter school each year with the foundation for intellectual curiosity and healthy development essential to academic success as they move along the education continuum.

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We believe that this goal can be achieved if the nation were to:

- **increase access to quality pre- and post- natal health care**

- **increase participation in child nutrition programs**

- **ensure that every pre-schooler has access to quality day care and early childhood education.**

- **enable all parents to better assume their roles as first teachers of their children.**

To make this goal a reality, we recommend that federal, state, and local governments:

- increase participation in the women, infants, and children (WIC) program so that by 1995, all the eligible participants are provided support.
- double the participation in child nutrition programs
- increase federal funding and state funding for child care programs to cover a 100% participation rate of pre-schoolers with mothers on welfare or for working mothers whose income is 150% of the poverty line.
- increase enrollment in head start incrementally over the next five years to cover 100% of the eligible population by 1995.
- invest in new approaches to easing and strengthening the home-to-school transition.

In our site visits we found numerous examples of successful intervention programs that work with minority children across the education spectrum. For purposes of this hearing, I will cite only a few. AVANCE, a parent education program in San Antonio, Texas, trains parents to assume their role as the primary teacher of their children. The Saturday Science Academy at the University of California at Irvine which requires Black parents to attend half the sessions with their children. The California Quality Education Project, with 100,000 students in 16 school districts, asks parents to pledge that they will set aside study time at home, get their children to school on time, read to children every day, attend back-to-school nights, and attend parent-teacher conferences.

A critical element in those successful intervention programs and in others was that most were conceived, developed, and implemented outside the local school system. To the credit of some of these systems, however, once these programs demonstrated their capacity to impact the targeted groups, or received broad community or political support, they were quickly incorporated into the regular school curriculum. Clearly there are lessons to be learned from these community based efforts.

Mr. Chairman, I urge you and your fellow committee members to include language within the reauthorization legislation under consideration this evening to allow these local initiatives to become the core of efforts designed to improve the quality of life in their communities.

Finally, minority community leaders and those of us who have achieved economic and educational success must take responsibility for our own people. Our energy, ideas, and money must return to the communities and to our children. No one can -- or should -- do it for us.

Chairman OWENS. Thank you.

Ms. Delia Pompa.

Ms. POMPA. Mr. Chairman, Mr. Payne.

On behalf of the Children's Defense Fund, I want to thank you for the opportunity to testify today regarding the reauthorization of the Early Intervention Program, Part H, and the Preschool Program of the Individuals with Disabilities Education Act. We at the Children's Defense Fund, or CDF as I'll refer to it from now on, applaud this committee's leadership and long-standing commitment to the implementation and exploration of quality education policy.

The Individuals with Disabilities Education Act, IDEA, is one of our nation's few bright spots in the realm of policies for children. It's comprehensive approach to early intervention has had what some call a revolutionary affect on American's disabled and disadvantaged youth. CDF is pleased to add its voice to the chorus of support for this successful legislation.

But IDEA can do more. Crippled by a deficiency in funding, many States have stopped expanding their Part H services and others threaten to discontinue their programs altogether. The most unfortunate result of this stagnation is the inability of States to expand Part H programs to at-risk children.

Part H of IDEA has the capacity, through its coordinated services, to not only help children who are already developmentally delayed, but also those who are at-risk of becoming so. The inability of States to take advantage of this unique opportunity is a problem that must be addressed at the Federal level. Only through increased funding and the proper incentives can IDEA reach its full potential.

Identifying a child as at-risk does not and should not impose a contrived label on that child. At-risk, as many have said before, does not seek to describe, only to warn. It raises a red flag over normal children whose normal histories or environments may lead to developmental delay. An at-risk child then is one who has a greater statistical chance of developing cognitive, physical or emotional problems than do his or her cohorts.

Public Law 99-457 encourages States to develop their own definitions of at-risk children, counseling them to include well-known biological and other factors that can be identified during the neonatal period and that place infants at-risk for developmental delay.

The following is a list of risk factors that the Children's Defense Fund believes should be included in States' definitions of at-risk. We believe strongly that sociologic and environmental factors, such as those which I will describe, are as important as biological ones in the healthy development of a child.

In particular, CDF is concerned with the fact that minority children are overrepresented in many of the at-risk categories which I will discuss. The poverty and poor health of many of our nation's minority children should be a constant reminder of how far we need to go before true equality is reached in this country.

While this list does not seek to be a comprehensive one, we hope States and the members of this committee will recognize the breadth of challenges facing our nation's youth and understand that a child who encounters more than one risk factor has an exponentially increased risk of becoming developmentally delayed.

Our first risk factor that we will list is poverty, and that's been discussed very eloquently by my colleagues here, but I'll tell you some more of the data we have. Poor children are less likely to receive key building blocks of early development, adequate nutrition, decent medical care, a safe and secure environment and access to early childhood development programs.

Growth retardation affects 16 percent of low-income children under the age of six. Poor children experience more sickness from infection and other debilitating conditions than the total population. Poor children are far more likely to be hungry, and those who are hungry are more likely to suffer fatigue, dizziness, irritability, headaches, ear infections, frequent colds, unwanted weight loss and inability to concentrate.

Poor children are more likely to be homeless. A figure that we use is that 40 percent of children in shelters are children under the age of three, so a major portion of children who are homeless are very young children.

Along with poverty, which we believe is the broadest indicator of at-risk, is low birthweight. As has been mentioned before, about 6.9 percent of babies born in the United States weigh less than 5.5 pounds at birth and are considered low birthweight babies. Low birthweight is one of the surest predictors of infant death or long-term disability.

Children born at very low birthweights are more likely than those born at normal weights to be inattentive, hyperactive, depressed, socially withdrawn, aggressively delinquent.

Follow-up studies of children born at low birthweights conclude that the influence of the environment far outweighs more effects of non-optimal prenatal or perinatal factors on outcome. Early intervention is as crucial in preventing these children from being developmentally delayed.

Children born drug-exposed. It is estimated that as many as 375,000 infants are born drug-exposed each year. For many of these children early intervention services targeted at special developmental health and mental health needs will be critical.

A portion of drug-exposed infants are infected with HIV. By February of 1990 more than 2000 cases of AIDS had been reported and diagnosed in children younger than 13. The rate of perinatally acquired AIDS increased nearly 40 percent between 1988 and 1989.

Moving on to the fourth risk factor, child abuse and neglect. 2.5 million children were reported abused or neglected in 1990. Child abuse and neglect has been linked to poverty, lack of medical care, homelessness, parental substance abuse and domestic violence. 69 percent of that large figure I gave you of abused and neglected children are under the age of five.

A problem that comes along with child abuse and neglect is a problem that we don't often associate with very young children and that is the risk factor of emotional problems. According to the U.S. Public Health Service 12 percent of all children younger than 18 suffered mental disorders in 1989. For many children emotional disorders are compounded by the stresses of poverty.

A sixth risk factor that we feel should be considered are postnatal complications. Public Law 99–457 identifies a number of other biological factors that place children at-risk of future developmental delays. Commonly cited factors include respiratory distress as a newborn, lack of oxygen, brain hemorrhage and infection.

Finally, a category that we feel needs to be looked at very carefully in deciding which risk factors should be used in serving children is the category of children born to teenage mothers. These children, especially those born to adolescents under the age of 17, are more likely than other children to display several of the risk factors that I've just described and are thus in a risk category of their own.

In 1985 and 1986, almost half of adolescent mothers had family cash incomes below the poverty line and nearly two-thirds were below one and a half times poverty. About half of all adolescent mothers receive welfare benefits sometime during the five years after they first give birth.

In 1988 one in seven infants born to mothers younger than 15 and one in eleven infants born to mothers ages 15–19 were born at low birthweight. In contrast, one in fourteen infants born to 20 and 24 year olds was born at low birthweight.

Early intervention strategies are extremely effective in preventing future disabilities and developmental delays. A penny spent today will save many pennies tomorrow; a dollar spent today will save many dollars tomorrow.

As the financial conditions in the States have worsened, as we heard earlier, and the States have realized the expenditure necessary to include at-risk children in their Part H programs, they have abandoned or stop expanding their at-risk services. Services to at-risk children denied the comprehensiveness and funding of Part H remain deficient.

We at CDF feel that this development is extremely unfortunate. We believe that one of the most important provisions in Part H is its optional services to at-risk children. Given the remarkable capacity to improve children's potentials, it is critical to evaluate at-risk infants as early as possible with an eye to sophisticated preventive and therapeutic measures. Early intervention truly does save many, not to mention lives, in the long run.

Consistent with these beliefs, CDF would like to make five recommendations to the committee regarding the reauthorization of the Early Intervention Program of the Individuals with Disabilities Act.

Recommendation No. 1. The law should specifically encourage States to include at-risk children in their Part H programs.

Recommendation No. 2. The law should permit States to offer a different scope of services provided to at-risk children. Two methods we suggest: we would allow States to narrow the services provided or assist existing Federal programs to serve at-risk children. Narrowing would help States accommodate at-risk children more easily. The law could be amended to serve at-risk children at the level of minimum routine periodic screening, tracking, monitoring and referral to existing services—an idea that I know several witnesses before this committee have endorsed.

Screening and monitoring can identify developing problems in at-risk children so that they can be served at the earliest possible time. States could also involve their Part H programs in activities which link them up with existing programs. And I would talk about such activities as information management systems where different social programs have access to the same information. We have children served by various social service agencies that don't communicate with each other.

Along with that, technical assistance to existing programs teaching them about at-risk factors and teaching them about ways their programs can be more involved in serving these children.

Recommendation No. 3. The law should set aside incentive funds to reward States that adopt plans to serve at-risk children. We feel that this is very important given the financial state that has been described here this morning in the States, and that we know exists. Incentive funds may be the only way we get this program off the ground for at-risk children.

Recommendation No. 4. The law should clearly identify Federal, State or local funding methods other than Public Law 99-457 that can be used to service the needs of at-risk children. A basic assumption of the Part H legislation was that States would use Part H funds for glue money mostly, and locate other sources to fund the early intervention services.

There is some, actually much, evidence that States have not been entirely successful in accomplishing this. While there are at least 16 Federal programs or potential services for Part H intervention, these programs are often under-funded themselves. Even when funds are available, coordinating other programs with Part H because of bureaucratic red-tape often poses a significant challenge.

An example I give is that of Medicaid. Medicaid funds, especially those earmarked for EPSDT or early and periodic screening, detection, and treatment programs, can certainly be used by States to service at-risk children. But in 1991, and I'll explain that that was completed last month, that recent, a CDF poll of 48 States revealed that only 15 percent of the States had written procedures between Medicaid and Part H for identifying and referring those who EPSDT assessment revealed Part H eligibility. Only 8 percent of the States collected information on Part H recipients who participated in other public programs. Only 17 percent collected data on the percentage of the Part H recipients who were Medicaid recipients also. So there is much work needed in how you coordinate those services.

Our final recommendation is that Congress should devote more funds to the set up and implementation of Part H programs that assist at-risk children. Despite the budget constraints faced by this year's Federal programs, we at CDF feel that the best way to improve an already effective program is to increase its funding. An earmarked Federal contribution to at-risk services under Part H may be the most effective incentive for getting States to provide programs for at-risk children.

Our proposals embrace changes only in the scope of the program. We feel that Part H of IDEA, while doing much for disabled and developmentally delayed children, could also be used in assisting children who are at-risk of becoming so.

Some funds are already available and additional incentives should be added to assist States in expanding their Part H services to at-risk children. Thank you.

[The prepared statement of Delia Pompa follows:]

No. 9

**Children's Defense Fund**
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BE GOOD TO ME
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# TESTIMONY
# OF THE
# CHILDREN'S DEFENSE FUND

BEFORE THE
SUBCOMMITTEE ON SELECT EDUCATION
COMMITTEE ON EDUCATION AND LABOR
U.S. HOUSE OF REPRESENTATIVES

HEARING
ON
THE REAUTHORIZATION OF THE
EARLY INTERVENTION PROGRAM AND THE
PRESCHOOL PROGRAM OF THE
INDIVIDUALS WITH DISABILITIES EDUCATION ACT

Presented by

Delia Pompa, Director
Education, Adolescent Pregnancy Prevention,
and Youth Development
Children's Defense Fund

May 6, 1991

**Mr. Chairman and Members of the Committee:**

On behalf of the Children's Defense Fund (CDF), I want to thank you for the opportunity to testify today regarding the reauthorization of the Early Intervention Program (Part H) and the Preschool Program of the Individuals with Disabilities Education Act. We at CDF applaud this Committee's leadership and long-standing commitment to the implementation and exploration of quality education policy.

As we near the end of the twentieth century, there is a growing national awareness that American children are not receiving the preparation necessary to meet the challenges of the next century. Unacceptable rates of childhood poverty, skyrocketing cases of preventable diseases, and growing numbers of children entering the foster care system are all indications of the scope of our country's crisis. How can we hope to educate children who come to school unprepared to learn? How can we continue to employ 'band-aid' remedies when early intervention strategies have been proven to be more effective and more cost-efficient?

The Individuals with Disabilities Education Act (IDEA) is one of our nation's few bright spots in the realm of policies for children. Its comprehensive approach to early intervention has had what some call a revolutionary affect on America's disabled and disadvantaged youths. CDF is pleased to add its voice to the chorus of support for this successful legislation.

But IDEA can do more. Crippled by a deficiency in funding, many states have stopped expanding their Part H services and others threaten to discontinue their programs altogether. The most unfortunate result of this stagnation is the inability of states to expand Part H programs to at-risk children. Part H of IDEA has the capacity, through its coordinated services, to not only help children who are already developmentally delayed, but also those who are at risk of becoming so. The inability of states to take advantage of this unique opportunity is a problem that must be addressed at the federal level. Only through increased funding and the proper incentives can IDEA reach its full potential.

**Defining 'At-Risk':**

Identifying a child as 'at-risk' does not, and should not, impose a contrived label on that child; 'at-risk', as many have said before, does not seek to describe, only to warn. It raises a red-flag over 'normal' children whose histories or environments may lead to developmental delay. An at-risk child, then, is one who has a greater statistical chance of developing physical or emotional problems than do his/her cohorts.

P.L. 99-457 encourages states to develop their own definitions of 'at-risk' children, counseling them to "include well-known biological and other factors that can be identified during the neonatal period, and that place infants at risk for developmental delay."

The following is a list of risk factors that the Children's Defense Fund believes should be included in states' definitions of at-risk; we believe strongly that sociological and environmental factors, such as those described below, are as important as biological ones in the healthy development of a child. In particular, CDF is concerned with the fact that minority children are overrepresented in many of the at-risk categories identified below. The poverty and poor health of many of our nation's minority children should be a constant reminder of how far we need to go before true equality is reached in this country.

While this list does not seek to be a comprehensive one, we hope states and the members on this committee will recognize the breadth of challenges facing our nation's youth, and understand that a child who encounters more than one factor has an exponentially increased risk of becoming developmentally delayed.

1. **Poverty:** Poor children are less likely to receive key building blocks of early development -- adequate nutrition, decent medical care, a safe and secure environment, and access to early childhood development programs.

   - Growth retardation affects 16 percent of low income children younger than six.
   - Poor children experience more sickness from infection and other debilitating conditions than the total population.
   - Poor children are far more likely to be hungry and those who are hungry are more likely to suffer fatigue, dizziness, irritability, headaches, ear infections, frequent colds, unwanted weight loss and inability to concentrate.
   - Poor children are more likely to be homeless; almost half the preschoolers in a 1986 study by Bassuk had at least one serious developmental lag and more than one-third had delayed language development. In Colorado, 35 percent of the children in the state's shelters in 1988 were younger than three.
   - Various aspects of mental function are different or deficient in children who do not receive adequate nourishment prenatally or immediately after birth.
   - In the mid-1980's, an estimated 3 million children, virtually all of them from low income families, had blood lead levels sufficient to place them at risk for impaired mental and physical development.

2. **Low Birthweight:** About 6.9 percent of babies born in the United States weigh less then 5.5 pounds at birth and are considered low-birthweight babies. Low birthweight is one of the surest predictors of infant death or long-term disability.

- Children born at very low birthweights are more likely than those born at normal weights to be inattentive, hyperactive, depressed, socially withdrawn, aggressive or delinquent.

- Many studies suggest that low-birthweight babies are more likely to suffer child abuse or develop learning disabilities and behavior problems than normal-weight babies.

- In 1987, about 48,750 babies were born at very low birthweights. Of those, 25-28 percent have borderline IQ scores, problems in understanding and expressing language or other deficits.

- Follow-up studies of children born at low birthweights conclude that the influence of the environment far outweighs most effects of non-optimal prenatal or perinatal factors on outcome. Early intervention is thus crucial in preventing these children from being developmentally delayed.

3.**Children Born Drug-Exposed:** It is estimated that as many as 375,000 infants are born drug-exposed each year. For many of these children, early intervention services targeted at special developmental, health, and mental health needs will be critical.

- Drug-exposed children are impaired in such taken-for-granted functions as sleeping and waking. Problems are also found in vision, motor control and in social interaction with others.

- Infants born to women who gained little weight during their pregnancy, who had smoked one pack of cigarettes a day and who tested positive for marijuana and cocaine averaged nearly a pound smaller than those born to women who had normal weight gain and did not use cigarettes, marijuana and cocaine.

- A portion of drug-exposed infants are infected with HIV. By February 1990 more than 2,000 cases of AIDS had been reported and diagnosed in children younger than 13. The rate of perinatally acquired AIDS increased nearly 40 percent between 1988 and 1989.

4. **Child Abuse and Neglect:** 2.5 million children were reported abused or neglected in 1990. Child abuse and neglect has been linked to poverty, lack of medical care, homelessness, parental substance abuse, and domestic violence.

- 69 percent of abused and neglected children are under the age of 5.
- Abused or neglected children who do not get treatment may be aggressive and distractable and have poor self-control. Many also suffer depression and low self-esteem, all of which can result in learning problems.

5. **Emotional Problems:** According to the U.S. Public Health Service, 12 percent of all children younger than 18 suffered mental disorders in 1989.

   - Some disturbances are biological in origin; others are the result of chronic maltreatment. For many children, emotional disorders are compounded by the stresses of poverty.

6. **Post-Natal Complications:** P.L 99-457 identifies a number of other biological factors that place children at risk of future developmental delays: "Commonly cited factors. . . include . . . respiratory distress as a newborn, lack of oxygen, brain hemorrhage, and infection."

7. **Children Born to Teenage Mothers:** These children, especially those born to adolescents under the age of seventeen, are more likely than other children to display several of the risk factors described above, and are thus in a risk category of their own.

   - In 1985 and 1986, almost half of adolescent mothers had family cash incomes below the poverty line and nearly two-thirds were below one and one-half times poverty. About half of all adolescent mothers receive welfare benefits sometime during the five years after they first gave birth.
   - In 1988, one in seven infants born to mothers younger than 15 and one in eleven infants born to mothers ages 15 to 19 were born at low birthweight. In contrast, one in fourteen infants born to 20- to 24-year-olds was born at low birthweight.

**Providing Services For At-Risk Children under IDEA:**

When the Early Intervention Program of the Individuals with Disabilities Education Act was first authorized, most states expressed interest in providing the law's optional at-risk services, indicating their understanding of a concept backed by multiple empirical studies; **early intervention strategies are extremely effective in preventing future disabilities and developmental delays.** A penny spent today will save many pennies tomorrow.

But this momentum has been stalled. As the financial conditions in the states have worsened, and as states have realized the expenditure necessary to include at-risk children in their Part H programs, they have abandoned or stopped expanding their at-risk services. Services to at-risk children, denied the comprehensiveness and funding of Part H, remain deficient.

We at CDF feel that this development is extremely unfortunate. We believe that one of the most important provisions in Part H is its optional services to at-risk children; given the remarkable capacity to improve childrens' potentials, it is critically important to evaluate at-risk infants as early as possible with an eye to sophisticated preventive and therapeutic measures. Early intervention truly does save money, not to mention lives, in the long run.

Consistent with these beliefs, CDF would like to make five recommendations to the Committee regarding the reauthorization of the Early Intervention Program of the Individuals with Disabilities Education Act:

1. **The law should specifically encourage states to include at-risk children in their Part H programs.**

2. **The law should permit states to offer a different scope of services provided to at-risk children.** Two methods we suggest would allow states to narrow the services provided, or assist existing federal programs serve their at-risk children. Many states are reluctant to provide at-risk children with the same breadth of services provided to already disabled and developmentally delayed children, primarily because of a lack of funds.

   Narrowing would help states accommodate at-risk children more easily. The law could be amended to serve at-risk children at the level of minimum routine periodic screening, tracking, monitoring and referral to existing services, an idea that several witnesses before this Committee have endorsed. Instead of promising early intervention services equal to those of disabled children, screening and monitoring can identify developing problems in at-risk children so they can be served at the earliest possible time.

   States could also involve their Part H programs in information management activities; existing federal programs such as AFDC could use technical assistance in identifying at-risk children and referring them to the proper sources of assistance.

   By providing the option to states of providing a different constellation of services to at-risk children and their families, P.L. 99-457 would encourage state participation while maintaining their flexibility.

3. **The law should set aside incentive funds to reward states that adopt plans to service at-risk children.** The Children's Defense Fund feels that it is in the best interests of the nation to keep a close eye on at-risk children; Part H of IDEA has provided the means, but not yet the funds, to accomplish this goal.

4. **The law should clearly identify federal, state or local funding methods other than P.L. 99-457 that can be used to service the needs of at-risk children.**

A basic assumption of the Part H legislation was that states would use Part H funds for glue money only, and locate other sources to fund the early intervention services. There is some evidence that states have not been entirely successful in accomplishing this. While at least 16 federal programs are potential sources for Part H intervention, these programs are often under-funded themselves. Even when funds are available, coordinating other programs with Part H, because of bureaucratic red-tape, often poses a significant challenge.

Medicaid funds, especially those earmarked for EPSDT programs, can certainly be used by states to service at-risk children. But a 1991 CDF poll of 48 states revealed that only 15 percent of the states had written procedures between Medicaid and Part H for identifying and referring those whose EPSDT assessment reveal Part H eligibility. Only 8 percent of the states collected information on Part H recipients who participated in other public programs; only 17 percent collected data on the percentages of Part H recipients who were Medicaid recipients also.

Some states have indicated their need of assistance in interpreting the recent amendments to the Medicaid laws. Others need help getting through the maze of bureaucracy to get things moving at a faster rate. Greater clarity and better coordination of services is certainly necessary if Part H is going to receive the funding it deserves.

5. **Congress should devote more funds to the set-up and implementation of Part H programs that assist at-risk children.**

Despite the budget constraints faced by this year's federal programs, we at CDF feel that the best way to improve an already effective program is to increase its funding. An earmarked federal contribution to at-risk services under Part H may be the most effective incentive for getting states to provide programs for at-risk children.

To conclude, neither our proposed definition of 'at-risk' nor our recommendations on reauthorization represent a change in the underlying philosophy and goals for the program. CDF applauds Congress and this Committee for implementing a program of the value of Part H of IDEA.

Our proposals embrace changes only in the scope of the program; we feel that Part H of IDEA, while doing so much for disabled and developmentally delayed children, could also be used in assisting children who are at risk of becoming so. Some funds are already available and additional incentives should be added to assist states in expanding their Part H services to at-risk children.

Thank you.

Chairman **Owens**. Thank you.

Dr. G. Gordon Williamson.

Dr. **Williamson**. I appreciate this opportunity to comment on the reauthorization of Part H. I'm Gordon Williamson, I'm on the board of the National Center For Clinical Infant Programs, on the Columbia faculty and also I'm serving as Director of the Coping Project at John F. Kennedy Medical Center in Edison, New Jersey.

And through these activities I've spent a great deal of my time addressing an issue that each of us faces daily, that is, how in the world do we cope with a stressful environment.

Particularly, I'm interested in how vulnerable infants and toddlers learn to manage the world. And in the studies that we've conducted it's absolutely clear that disabled infants and toddlers, as well as those living in poverty as a group, have much greater difficulty coping with every day activities in terms of meeting their own needs and being responsive to the environment. You look at the coping styles of many of these kids and they're erratic; they're inflexible in their limited range in terms of ability to meet their needs.

A case in point is a six-month old girl, Leticia, who I saw only last week in Newark who lives with her mom, three brothers and a grandmother in a crowded two room apartment. And due in part to prenatal drug-exposure she is a very tense baby, hypersensitive and jittery, just as Dr. Griffith discussed earlier. So the concern becomes how does Leticia learn to fall asleep when the lights are always on and the radio is blasting. That television never is off 24 hours a day. The question becomes how does she manage to get her wet diaper changed and her emotional needs met when she has a mother who's physically exhausted, clinically depressed and is too absorbed with her own pain.

The point that was said earlier, I think, is a critical one; the point is that we know how to help the Leticia's, her moms and other children. Somehow currently in our society we have this defeatist notion that these problems are insurmountable; the point is that they're not; we have documented effective programs.

I think our greater challenge is developing community systems of how these programs work together, but we know what to do. And it seems to me our challenge is: are we going to help, and how can Part H make the contribution?

Now, I personally think that this is really unique legislation. It looks at infants and toddlers in a comprehensive view, it has a concern for interagency coordination, and most of all it's family-centered if parents are major decision makers. And I think it's really critical that in these times of physical constraint, when we get only absorbed in regulatory constrictions, that we lose sight that this is truly a unique vision that is exemplified in this legislation, and that we recognize that systems development is long-term and it's incremental and that we encourage the States to hang in there and keep building.

Because one of the things that I have been surprised at, well pleased I should say, is how many States really want to be responsive to these infants; they're just running scared. And so what I would like to do is give four or five recommendations that I think can hold the States and expand their commitment to these children.

The first is that we really need to reinforce in the reauthorization the congressional intent that we serve these infants, that States have a responsibility regardless of whether or not they include them in their definition of eligible for early intervention services. I agree with what some other people have said. Even though States may not be willing right now to serve this population, or if so they have found it fairly narrowly, let's at least encourage them to connect these kids up with identification, screening, and tracking and focus on multi-risk factors in terms of the monitoring and build in a system that follows these kids over time.

Also, if we can build a little parent support and service coordination in with these systems we can ensure that our early identification system is building provision as well as identifying those children at greatest risk for referral to more comprehensive services so one is really expanding our child find efforts so that we make sure these kids are included.

The next is the public awareness component of Part H. I'm a big believer that we need to increase the understanding of the public about risk factors, how they impact on child and family, early indicators of them, and available resources.

Everyone in this room knows that if you've got an emergency you call 911. But who in this room knows that if your baby needs her eyes checked where do you go; when does she need her shots, and what do I do if I have concerns about her sleeping and feeding. So that these are the kinds of issues that I think we need to start incorporating in our public awareness in the central directory so it goes beyond just identifying these early intervention resources but takes a much broader view that cuts across prevention, child care and other resources.

So at least in our public awareness and central directory we're making some of these linkages.

Another point is I think it would be very helpful if Congress expands on what they mean by the meaning of early intervention services; that is, eligibility is for multi-disciplinary assessment and an appropriate collaboratively determined individualized service plan, not an automatic eligibility for a pre-established array of comprehensive services. The nature and extent of participating in the early intervention program should be highly variable and personalized among families and there should be an array of service options.

It's absolutely legitimate that some early intervention services are less costly and low intensity.

They may be just surveillance of the child's development, input and some consultation to the child care provider and maybe some information for the parent.

The reason I bring this up—restricting their eligibility because of discussions that reflect a perspective that all infants require highly intensive specialized therapeutic and educational services. I think this idea of we're opening it up so every kid is going to need this whole roster of services is driving the debate and constricting our focus. And I think some of the early testimony in this session is representative of this concern that I have.

Another issue is that we need to shift our terminology in terms of the developmental domains from psychosocial to social emotional/development and from self-help skills to adaptive development. I think these terms are more pertinent to young children and even more so, they're really pertinent in terms of a lot of our interest in at-risk children.

Informed clinical opinion is particularly critical in the assessment of these two domains—social/emotional development and adaptive development. Norm-referenced, standardized tests are frequently insensitive to delayed or atypical development in these areas and other methods are indicated such as parent interview, adaptive behavior measures and observations of the child's play and interaction with others.

The statute needs to provide a definition of informed clinical opinion and procedures to ensure its use. There is concern, and I'm absolutely convinced, that many at-risk children are not served due to eligibility criteria that only rely on single test performance, many of which are culturally biased and neglect the relevance of multiple sources of information and clinical judgment.

I'm just going to highlight two others. I think the Federal Interagency Coordinating Council needs to be expanded so it focuses on reviewing the wide scope of the legislation that's out on that table and that the Congress assist in clarifying with Federal agencies their physical and programmatic responsibilities for implementation of Part H. I'm particularly interested in having the Department of Agriculture because of its—programs involved as well as the Social Security Administration because of the expanded eligibility criteria of SSI. It is very hard for an infant to be successful if it's cold and hungry.

And then lastly, we need to expand the Children With Disabilities Early Education Program. That's that program that provides for model demonstration, outreach, research initiatives; really providing incentives for them to look at at-risk children, to relate that network with the network that's part of the Bureau of Maternal and Child Health. They tend to be going in parallel tracks.

And I have also emphasized somewhat in my testimony some of the areas for special attention, one of which is looking at the incidence prevalence and prevalence in identification of very at-risk populations.

Another one which I know, Congressman Owens that you're particularly interested in, is the training of paraprofessionals to work with at-risk children within their communities. This is an area where I think this early education program network could really develop some more effective models to further that perspective.

In conclusion, a teenage mom receiving early intervention services told me just recently, "my baby and I have a future now; I know what to do and how to do it." The point is, early intervention works; our task is to make it even better. Thank you.

[The prepared statement of Dr. G. Gordon Williamson follows:]

# STATEMENT TO THE
# U.S. HOUSE SUBCOMMITTEE ON SELECT EDUCATION

## WITH RESPECT TO
## REAUTHORIZATION OF PART H
## OF THE
## INDIVIDUALS WITH DISABILITIES EDUCATION ACT

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# STATEMENT AND RECOMMENDATIONS

G. Gordon Williamson, PhD, OTR

I appreciate this opportunity to comment on the reauthorization of Part H of the Individuals with Disabilities Education Act. Over the past seven years I have been a co-director with Shirley Zeitlin, Ed.D. of the Coping Project at the John F. Kennedy Medical Center in Edison, New Jersey (supported in part by grants from the Children with Disabilities Early Education Program, Office of Special Education Programs, U.S. Department of Education). The purpose of this project is to assist early intervention and preschool practitioners to implement services that support the adaptive capabilities of families with children who are disabled or at risk regarding their functional outcome. As part of our work, we developed the Early Coping Inventory to measure the coping styles of children under three years of age. In the process of establishing its psychometric validation, data were collected from a large, field-based sample of children with and without disabilities.

This investigation found that as a group infants and toddlers who are disabled or at environmental risk due to poverty coped significantly less effectively than their non-disabled and more economically affluent peers. Their coping behaviors were more erratic, inflexible, and restricted in range of available adaptive strategies. This finding is consistent with studies of older children from these two groups. The essential point of this discussion is that the field is becoming increasingly more adept at identifying early behavioral characteristics of infants that interfere with their ability to make adaptations to meet their personal needs and to respond successfully to the demands of their surroundings. Our challenge is to assist these children and their families to expand their coping resources through a service system that links prevention, early identification, early intervention, and related family support efforts.

PL 99-457, Part H is truly unique social legislation due to its comprehensive view of the needs of young children, its emphasis on community-based coordination of health, developmental, educational, and social services, and its family-centered approach with parents as active decision-makers. From a longitudinal perspective this legislation has the potential of serving as a major catalyst to harness public and private resources into an integrated service delivery system that is ultimately responsive to all infants and toddlers at significant risk of delay or disability. In these times of fiscal constraint, it is important not to lose sight of this vision and to recognize that systems development is a long-term, incremental process. My comments are shared regarding ways to serve the broadest range of children with special needs given these realities.

1. The reauthorization should express congressional intent that states serve at-risk children whether or not they include them in their definition as eligible for early intervention services. The statute should allow Part H funds to be used for comprehensive child-find efforts to include identifying, screening and tracking these children as a cooperative interagency activity. A serial, multivariate approach would monitor multiple risk factors over time with an appreciation of the context of the child's caregiving environment. Such a system can be designed to incorporate some level of service coordination and family support. Thus preventive components can be integrated into the early identification system and referrals made for those children who are at greatest risk.

2. The public awareness component of Part H should be expanded to increase understanding of at-risk factors and their impact on child and family well-being, early indicators of atypical behavioral and developmental patterns, and the availability of a wide range of community services, including those that traditionally extend beyond the early intervention network (e.g. neighborhood-based programs, child care centers, family day care). These diverse programs and services can be incorporated into the state's central directory to encourage linkage of community service systems.

3. Additional guidance is required related to the meaning of eligibility for early intervention. That is, eligibility is for a multidisciplinary assessment and an appropriate, collaboratively-determined Individualized Family Service Plan rather than automatic eligibility for a preestablished array of comprehensive services. The nature and extent of participation in the early intervention system should be highly variable and personalized among families along a continuum of service options. Appropriate services for some families may legitimately be low-intensity, economical interventions such as information regarding community resources, periodic consultation to the child's day care provider, and developmental surveillance. This issue warrants attention since a number of states are presently narrowing their scope of children to be served based on discussions that reflect an orientation that all families will require highly intensive, specialized therapeutic and educational services.

4. Terminology needs to be amended regarding the developmental domains addressed in the evaluation and assessment. Social/emotional development and adaptive development are more pertinent and generally accepted terms for young children than psychosocial development and self-help skills. Informed clinical opinion is particularly critical in the assessment of these two areas. Norm-referenced, standardized tests are frequently insensitive to delayed or atypical development in these domains and other methods are indicated such as parent interview, adaptive behavior measures, and observations of the child's play and interaction with others.

The statute needs to provide a definition of informed clinical opinion and procedures to ensure its use. There is concern that children are not served due to eligibility criteria that over-rely on single test performance and neglect the relevance of multiple sources of information and clinical judgement.

5. The Federal Interagency Coordinating Council should review all federal prevention and early intervention programs and take a leadership role in promoting joint interagency planning to achieve coordination of services. It is particularly important that Medicaid, child care providers, and the public and private health care system are integrated into the service matrix.

Chairman **Owens**. Thank you.

Marji Erickson.

Ms. **Erickson**. Thank you, Chairman Owens and Congressman Payne, it's a pleasure to be here.

My name is Marji Erickson. I'm an Associate in Pediatrics at the University of Massachusetts Medical School, and later this month I will receive my Ph.D. from the Heller Graduate School for Social Welfare Policy in Waltham, Massachusetts.

To complete my degree, I conducted a study that estimated the costs of one year of early intervention services for different groups of infants and toddlers with a wide range of developmental delays or disabilities.

The developmental gains each group made after one year of early intervention services were also studied. These included gains in cognitive skills and adaptive behavior, which encompasses communication, daily living, motor, and social skills. Also included were gains in the child's ability to interact with his or her mother.

The data for this project came primarily from the Early Intervention Collaborative Study which is supported largely by a grant from the Bureau of Maternal and Child Health and Resources Development. Data were also gathered from 25 publicly-supported early intervention programs in Massachusetts.

The 157 children who were studied can be categorized into two main groups. The first group includes children who are mandated to receive early intervention services under Part H of Public Law 99-457. This group includes children with a diagnosed medical condition such as Down syndrome or cerebral palsy. The second group includes children without a diagnosed disability. Many of these children are developing more slowly than expected and will be categorized as biologically at-risk.

In many States children are not eligible for early intervention services unless they are demonstrating a significant delay in their development. Thus, many of the children in the second group that were studied would not have been enrolled in an early intervention program until the magnitude of their delays exceeded an arbitrary level.

A primary goal of the Part H program is to reduce future educational costs by minimizing the need for special education and related services after these children reach school age. Although my study was not designed to investigate whether this specific goal can be realized, the findings suggest that this objective may be better served by broadening the Part H target group to include these children at-risk who have milder delays without specific diagnoses.

In fact, the findings suggest that although these children with milder delays can be helped regardless of when they enter early intervention, those who enter earlier gain more. Thus, States should be more aggressive in identifying children with subtle problems and in providing services to them as early as possible.

I want to highlight two specific results from my study which support these statements. First, the group of children with milder delays who entered early intervention before their first birthday received a modest amount of services.

In contrast, children with milder delays who are older than one year of age when they entered early intervention, as well as children with more severe disabilities of all ages, received a greater number of service hours.

These differences in service provision were reflected in the expenditures that were analyzed. The expenditures for the younger children with milder delays were lower than those for all other children. The second result indicated that the younger group of children with milder delays also experienced greater gains in the three measures of development than all the other types of children.

After combining these two results, the younger group of children with milder delays was found to have experienced greater gains per dollar than all the other types of children. In summary, the younger group with milder delays was served more effectively for a lower level of cost.

Several key policy implications may be drawn from these results. First, the greater gains per dollar associated with the younger group with milder delays suggests that States might benefit from a greater focus on child find and referral services for children with more subtle difficulties. Such services may be able to identify children when they are still less than one year of age and may be experiencing only mild delays.

Second, these results suggest that States should consider broadening their definition of developmental delay. Very narrow eligibility criteria ban the provision of services to younger children with milder delays who make the largest gains per dollar. Importantly, if services are provided to these children very early on, it may be possible to reduce the amount of special education and related services they will require later. Thank you.

[The prepared statement of Marji Erickson follows:]

No. 11

TO: Pat Laird

DATE: May 1, 1991

FROM: Marji Erickson

SUBJECT: Written Testimony for May 6th Congressional Hearing

Good afternoon. My name is Marji Erickson. I am an Associate in Pediatrics at the University of Massachusetts Medical School and later this month I will receive my Ph.D. from the Heller Graduate School for Social Welfare Policy in Waltham, Massachusetts. To complete my degree, I conducted a study that estimated the costs of one year of early intervention services for different groups of infants and toddlers with a wide range of developmental delays or disabilities. The developmental gains each group made after one year of early intervention services were also studied. These included gains in cognitive skills and in adaptive behavior which encompasses communication, daily living, motor, and social skills. Further, improvements in the quality of the child's ability to interact with his/her mother were also studied. The data for this project came primarily from the Early Intervention Collaborative Study (EICS), which is supported largely by a grant from the Maternal and Child Health Bureau of the Department of Health and Human Services. Data were also gathered from 25 publicly-supported early intervention programs in Massachusetts.

The 157 children who were studied can be categorized into two main groups. The first group includes children who are mandated to receive early intervention services under Part H of PL 99-457. This group includes children with a diagnosed medical condition, such as Down syndrome or cerebral palsy. The second group includes children without a diagnosed disability. In many states, such children would not have been eligible for early intervention services unless they were demonstrating a significant delay in their development. Instead, many of the children in this latter group would be categorized as biologically at-risk and would not be enrolled in programs until the magnitude of their delays exceeded an arbitrary level.

A primary goal of the Part H program is to reduce future educational costs by minimizing the need for special education and related services after these children reach school age. Although my study was not designed to investigate whether this specific goal can be realized, the findings suggest that this objective may be better served by broadening the Part H target group to include children "at-risk" who have mild delays without specific diagnoses. In fact, the findings suggest that states should be more aggressive in identifying children with subtle problems and in providing services to them as early as possible.

I want to highlight three specific results which support these statements. First, the group of "at-risk children" who entered early intervention before their first birthday received a modest amount of service. In contrast, both the groups of children with milder delays who were older than one year of age when they entered early intervention and the groups of children with more severe disabilities received a greater number of service hours. These differences in service provision were reflected in the expenditures associated with each group. Thus, the expenditures for the younger group of children with milder delays were lower than those for the other groups.

Second, the younger group of children with milder delays also experienced greater gains than the other groups in all three measures of development. After combining these results, the younger group of children with milder delays was found to have experienced greater gains per dollar than each of the other groups. In summary, the younger group with milder delays was served more effectively for a lower level of cost.

Several key policy implications may be drawn from these results. First, the greater gains per dollar associated with the younger group with milder delays suggest that states might benefit from a greater focus on child find and referral services for children with more subtle difficulties. Such services may be able to identify children when they are still less than one year of age and may be experiencing only mild delays. Second, these results suggest that states should consider broadening their definition of developmental delay. Very narrow eligibility criteria ban the provision of services to children with milder delays who make the largest gains per dollar. Importantly, if services are provided to these children very early on, it may be possible to reduce the amount of special education and related services they will require later.

Chairman **Owens**. Thank you. You make a compelling and united case. Budget decision makers and politicians may decide to do things for the wrong reasons but it sounds as if the professional judgment is unanimous in this area of at-risk—the benefits to be gained by early intervention for at-risk children. We have invited people who almost all agree with each other.

Can you tell us whether in the field there's a body of evidence that somebody is offering to the contrary or are there any persons who say that the prevailing opinion here is not the correct one?

Mr. **Charles**. I'll speak to that point. I don't think that there's anyone who would disagree with the importance of early intervention. Where you get a level of disagreement is where people looking at that whole spectrum for higher education, community colleges, you get an argument about where intervention should take place, primarily because one looks at immediate impact. If one is trying to address the issue of the shortage of minorities in math, science and engineering, professional technological fields, one makes the argument that we have to start at the time of conception that people have sometimes put off.

But then they move at the other end of the spectrum, they say we need to intervene in high school, we need to intervene in the freshman and sophomore year in college and so forth. Eventually when they look and the pool is dried up, there are not enough young people available to move into those areas with the qualifications necessary to proceed. Then they simply say what we ought to do is go back.

So in all the meetings and all the hearings we had all over the country, plus all the years that I've been in this field, 35 years, people always come back eventually—if we only started earlier. So I think we're in general unanimous agreement that starting earlier is the strategy in terms of where you had put your resources.

Dr. **Griffith**. I think the one area that was brought up by Dr. Williamson is a critical one. The one area of some disagreement, not necessarily among the professionals but early among legislators and people playing budgets, is one that's very crucial, and that is the belief that if you're providing an early intervention for all children you're providing the same level and cost and comprehensiveness of services.

And that's very crucial in that the earlier you diagnose and find even subtle problems, as was pointed out by Ms. Erickson's study, the less it's going to cost and the less comprehensive the service has to be.

On the other hand, if you take that same child and wait until he's 3 or 4 or 5 years of age and has been exposed to additional risk factors, then the cost is much greater and the need for service is much larger.

Chairman **Owens**. I don't know how many of you were here when I spoke earlier to Dr. Noonan. I asked the question, does New York include at-risk children in its program or not? In his testimony, he talked about identification, screening and tracking as being part of the system. In fact, he repeated it several times in different ways. And I was wondering does New York include it or not? Now you say that you can have a different scope.

And I think, Dr. Williamson, you said identification, screening and tracking are what's most important. Likely, that's going to be interpreted as being sufficient——

Dr. **Williamson**. Clearly, if the political climate wasn't what unfortunately it is, I would want that discretionary part of at-risk in terms of eligibility to be required so that all States would have to be serving at-risk children.

But the reality is that we're not there yet. And part of what my message was is that we have to be developing the system gradually over time. And so if could—some States indeed are including some categories of at-risk as you had mentioned earlier, and even for those who choose not to include them in terms of eligibility for the roster of entitlements, they're also concerned about them in terms of early intervention services.

Even if they choose not to include at-risk in their definition of children to be served, what I'm suggesting is that Congress at least says—makes it clear—that you can spend Part H funds to do at least an identification, screening and tracking service, and then with your central directory you can really start linking at-risk kids within that central directory of information. And then through your public awareness you can start assisting others to be aware of the wide range of available community resources.

So clearly I wish that we were in a State that it was just given that at-risk kids would be served. But the reality is that we'll probably—well it's going to be a small percentage, I'm afraid, particularly given the way the climate is evolving, of States that are going to include it.

I think part of the issue in terms of at-risk, I think we all agree that these early intervention services are really powerful, they really are effective. The issue though is if you wanted to choose—at-risk populations you want to address, that's where I think we don't have a lot of the data.

I mean we talk about multiple risk, but does that mean we want a teenage mom living in poverty whose kid is drug-exposed prenatally or do we want a child who is low birthweight—and is homeless.

Chairman **Owens**. You have to make those kinds of choices?

Dr. **Williamson**. Well, I guess my point is that the issue in terms of—folks have to start deciding what at-risk factors they're going to try and what combination.

Chairman **Owens**. The two examples you cited were kind of extreme; both of them really.

Dr. **Williamson**. Exactly. But the point is that in reality the States are going to have make decisions if they choose to serve at-risk: which of those at-risk factors they're going to include in terms of eligibility or if they're going to track which factors are the most potent. And I think that's why your testimony was very helpful because you really identify some of those that you think are the most critical.

Ms. **Pompa**. What I wanted to add to that is that I think incentive grants would go a long way. I——

Chairman **Owens**. I wanted you to spell it out, Ms. Pompa. It will be good to have on the record what you mean by "specifically encourage the State" and "offer more incentives;" even some dollar figures. It would be good for the record if it came from you instead of from us.

Ms. POMPA. I'm afraid I don't have dollar figures——

Chairman OWENS. You don't have to have——

Ms. POMPA. [continuing] but I can give you an outline of what——

Chairman OWENS. Even if you don't have them today——

Ms. POMPA. [continuing] because I'd be glad to do that.

Chairman OWENS. You could submit additional——

Ms. POMPA. I will do that——

Chairman OWENS. [continuing] statements in writing from the Children's Defense Fund with recommendations in that area.

Ms. POMPA. Because I think the incentive funds can go a long way toward expanding what we're all talking about. It's clear that with the budget constraints the States are facing, they're going to serve the children; they don't have the money; that programs that are supposed to serve the kids are under-funded—developmentally delayed now.

But if you look at what various States have undertaken for their school age children, those in say kindergarten through grade 12, many of the States have developed at-risk definitions for those children. An incentive grant might allow the State to take what's going on in the school and hook it on to what's happening in the other social service agencies.

Such things as information management systems that would allow you to track children; staff development or technical assistance to agencies to help them identify the children and figure out ways to work together, are the kinds of activities that could fall under incentive grants to get this going.

I'm afraid what happens at the Federal level a lot of times is we tell States coordinate, coordinate, collaborate and we forget how much time in terms of personnel and resources it takes to get together to collaborate. So I believe the incentive funds would be used very effectively in that put together some model programs to do exactly that for at-risk children. And I'll be glad to provide you some figures and some specifics later on.

Chairman OWENS. Thank you. Please submit any more specific recommendations on the area of incentives, encouragement, and ways in which most States could be enticed to do the right thing. Thank you very much.

Mr. Payne.

Mr. PAYNE. As you indicated, I think that everyone at the other table certainly has the same opinion that we have. If you were all the members of congress we'd have no problem. But I would certainly like to say that I think that advocate groups are really going to have to speak out a little bit more forcefully.

An interesting thing happened this year as relates to the WIC Program. As you probably know for the past two or three or four years, in particular a group of CEO's from the Middle Atlantic States have actually been meeting together in New Jersey, a group headed by Bob Winter from Prudential, CEO of Prudential, have been holding meetings quarterly in regard to the WIC Program.

And as you know, about two or three months ago, five CEO's from AT&T and Prudential and several other large corporations testified before the Budget Committee.

And the WIC Program for the first time will be fully funded over a five year period by 1996, or 1997, adding about $3.5 million annually to bring the program up to about 4.1 billion by 1997 adding another maybe billion and a half.

It was because there were advocacy groups. They were pushing because as it's been indicated you should start with remediation. And years ago I taught in a secondary school and I said I need to get these kids a little earlier, in high school its to late to reach, they're lost; it needed to start in junior high.

I left there and went to an elementary school, but they were still coming unprepared and so forth.

It is great that the WIC Program will be fully funded. That doesn't mean everyone is going to take advantage of it. Those who do are still going to have problems. It's unfortunate that we can't take the next step of these at-risk youngsters.

But as you've indicated, and we know especially in New Jersey, the budget presents a very difficult situation even with increased taxes and cuts we find that there's still a wide budget gap. If a State like New York is not going to pick it up, you know that we're not going to see it in other States, such as in border States and in the south and in the west.

So I really don't have any questions, Mr. Chairman, I just want to reiterate the need for these programs and perhaps the organizations could be helpful in lobbying once we get a plan going. But I certainly appreciated all of your testimony, it's very accurate and very clear and very helpful. Thank you.

Chairman Owens. Thank you again members of the panel.

We have a list of people who wanted to testify during the open mike session. However, some have left. Please give your name and organization at the beginning of your testimony. Thank you.

I would like you to try and limit your testimony to two or three minutes.

## STATEMENT OF FELICE BURNS, MEMBER, BOARD OF DIRECTORS, CITIZENS COMMITTEE FOR CHILDREN OF NEW YORK

Ms. Burns. Good evening. My name is Felice Burns and I'm a member of the board of directors of the Citizens Committee for Children of New York which is a 47 year old multi-issue advocacy organization dedicated to improving conditions for New York City children.

I am pleased to be here today to speak to you about the reauthorization of Public Law 99-457, Part H program for infants and toddler and to thank you Congressman Owens and staff for this important opportunity.

To start, I want to express our commitment to the Part H program and to its full implementation in New York State. Unlike other programs serving young children, the Part H program mandates family-focused services and expects professionals to work across agencies to develop an early intervention system that identifies, refers and places children with handicapping conditions.

As you know, the Part H is unique because it requires that the early intervention system integrate existing resources into a comprehensive system providing infants, toddlers and their families with the services they need in the most appropriate setting.

We view the Part H program as both progressive and challenging, recognizing as it does the role of families in addressing problems arising from the new morbidity, poverty, homelessness and hunger. And for these reasons we support the reauthorization of the Part H program.

One issue being considered is whether to grant extensions to States that may be not be able to comply with the program timewise. We know that Part H was developed so that States would have the program fully operational by year four, and we believe that perhaps the timetable is too short.

Current conditions now suggest the need for an extension to make it possible for States like New York to participate. First, Part H organizes services in a way that changes how agencies are used to doing business; thus, the planning and implementation of this program has been much more difficult and time consuming than we expected five years ago.

Second, many States, including New York, have been stricken by fiscal crises that have significantly slowed the momentum to enact legislation and to begin the implementation of the program.

The budget crisis and Part H's radical departure from the way services are presently organized, has delayed implementation and in New York State has led us to develop a two-prong advocacy approach. In New York State this means that we must work towards passing the Early Care Bill this year, and if fiscal realities deem this impossible, to wholeheartedly support an extension that enables us to remain in the program.

Another issue in reauthorization discussions is the level of appropriations. In year four Congress is expected to award New York State approximately $5 million. In exchange for this grant, the State is expected to have the majority of Part H's fourteen required components fully operational.

However, implementing many of these components will cost New York State more money than is currently available. Although Federal planning dollars covered certain planning and start-up costs, we will only be able to tap into other funding streams like Medicaid to cover the cost of certain services. Some of Part H's new required components are not of New York's existing early intervention system and are not funded.

Implementing these new components like care coordinators, child find, and training will be difficult for both the State and county with deep budget deficits. And for this reason, Congress must increase the grants to the State.

The Citizens Committee has wrestled with whether to advocate the inclusion of at-risk children in the New York State definition of eligible children. While we clearly support early intervention as a way to prevent later developmental problems, we also understand that fiscal realities make it impossible for States and counties to serve all infants and toddlers in this program solely on the basis of risk alone.

To illustrate, in New York City where at least 60 percent of approximately 360,000 children under three are poor, this population is virtually limitless. Furthermore, in New York City, as in other places, we know that the burden of poverty falls disproportionately on minority children and families. More than one out of every two Hispanic children are poor and more than two out every five Black children are poor, contrasted with one in every white child being poor, sorry, I don't have the figure, one in every five, I think.

Poverty is not the only risk that preys upon our city's young children. AIDS was the leading cause of death for children 1-4 of age years in 1987. 15,000 will be born this year exposed to drugs, and 24 percent are without health insurance. Clearly, there must be some mechanism to link these at-risk children to early care.

Citizens Committee believes that there is. The Part H program mandates that any child find system that includes infants and toddlers that are potentially eligible for Part H services, including Medicaid's early periodic screening, diagnosis and treatment program, supplemental security income, Head Start and maternal and child—be coordinated within the State's early intervention system.

A coordinated child find and tracking program would allow infants and toddlers to be monitored and referred to the local early intervention program, if any delays are detected in a developmental screen.

For instance, using the mandate of EPSDT eligible at-risk infants or toddlers could be linked to an EPSDT provider who is mandated to provide developmental screening based on the guidelines established by Medicaid with the assistance of the American Academy of Pediatrics.

An infant under one, for example, should have screenings at one month, two months, four months, six months, nine and twelve months. If a delay were identified at any point, the infant would be automatically referred for more comprehensive screening through the early intervention program.

The Part H program gives policy makers and providers an opportunity to implement a landmark program for young children and their families. We must meet this opportunity with compassion and vigor and urge you to reauthorize Part H with increased appropriations and extensions for States. Thank you.

Chairman **Owens**. Thank you. And you're accompanied by Ms. Kathleen Noonan?

Ms. **Burns**. Yes. She's on staff at Citizens Committee. She's just with me.

Chairman **Owens**. Then we have Ms. Susan Sokol and Ms. Henna White of the Hebrew Institute for Deaf and Exceptional Children.

## STATEMENT OF SUSAN SOKOL, DIRECTOR, DAY CARE AND GIANT STEP PROGRAM, HEBREW INSTITUTE FOR THE DEAF AND EXCEPTIONAL CHILDREN ACCOMPANIED BY HENNA WHITE, MOTHER

Ms. **Sokol**. I'd like to thank you for giving me the opportunity to speak at this time, and just to raise a few issues that we meet up against every day.

I'm Susan Sokol. I'm the director of the day care and giant step program at the Hebrew Institute for the Deaf and Exceptional Children.

HIDEC, as we call ourselves, is a non-public school having many different programs. We're unique in that we service the special education pre-school child age 2–5 in self-contained classrooms. All of these children receive all related services including speech and language, occupational therapy, counseling and physical therapy.

We are a recognized evaluation and diagnostic center with the New York City Board of Education and New York State Education Department. We have a medical staff consisting of a doctor two afternoons a week, and a full time nurse, and a full time audiologist.

We also have a day care and giant step program consisting of the normal preschool child and also the special education child. We have a mainstream, integrated class which is unique in many ways. It houses within one class the special education child who receives itinerant services along with the normal child. They both attend the same classes, and the special education child receives the related services that he's entitled to and mandated by the Committee on Special Education.

However, the problem that we've run up against is that there's no mechanism in place for who's going to pay for these related services. There is no one out there who is footing the bill for the speech and language therapy, for the occupational therapy that these children in the day care class ages 5–6 are receiving.

Children up till 5 are being taken care of by the Committee on Preschool Special Education through the Board of Education. Children between the ages of 5 and 6 are slipping through the cracks. And they are receiving the services, we're providing those services, but we're picking up the bill for it.

There's also a transportation issue that the children are—there's no transportation for day care children. Parents have to bring these children and pick them up and bring them back and forth. And the children who are receiving itinerant services and who are at high risk, deserve to have this transportation. And many times children have to be taken out of our program because the parents cannot afford to pay for the transportation.

Outside of this mainstream, integrated class we have a group day care class, children 2½ to age 6. Many of these children are not handicapped enough to be eligible for related services but are part of a high risk population of which we're seeing more and more of. These children come from families, broken home families, families that have drug involvement, families of abused spouses or parents and two parent families that are overstressed due to the difficult financial crunch that everyone in our city, unfortunately, has been exposed to.

These parents have resorted to child abuse as an outlet for the overstress that they have to bear. The parents of these children need parenting skills, training and support. Counseling for parents of our children from these homes is available. We do have a psychologist, a social worker, and a nurse; they're all part of our staff, and they are available to our parents at a minimal time and minimal restraints because of, excuse me, at a minimal amount of time due to financial and time constraints.

There are no provisions for these support systems to day care children. We try to refer out to agencies but they're overbooked and the time frame is difficult to work with. Many parents have just dropped out of the system because of the difficulties they meet up against.

With appropriate intervention, children can maintain development in emotional, social, attentional, behavioral and cognitive areas and hopefully move into a full time mainstream placement.

Chairman **Owens**. Thank you.

Ms. White, do you want to amplify?

Ms. **White**. Thank you. Excuse me, I'm a little nervous. I come here in a totally different capacity to anybody who has spoken today. I come as a mother, and I appreciate that you're giving me the opportunity to put forward how I feel as a special education mom, somebody who's been through from very early age children with special needs.

I have three boys who are hyperactive. When I say hyperactive I mean these are little boys who literally climb walls, putting a lot of guilt on a mother, as I used to wonder what am I doing wrong, is it something I'm not controlling. It's a very low key situation and you have a hard time knowing where to go to and who to speak to, and it took a long time to get to the right sources.

And we now have two of the boys in an integrated mainstream program, and the other, the second little boy whose problems are on the borderline, he's not hyperactive but he has hyperactive tendency and is a high risk child, is in the group program at HIDEC.

Also, as I said before, it's very low key and a parent doesn't know where to turn. And there are programs that now help out parents, but there's still sometimes even simple situations you don't know where to turn and sometimes I feel I wish there were more places that they could go to.

One child—that's certain amount of pressure off myself and the teachers. And I've been told to put this child into a structured environment. And with the two of us we learned to work together as a family with the help of day care and all the people involved. Thank you.

Chairman **Owens**. Thank you.

Jane Rubinstein.

## STATEMENT OF JANE E. RUBINSTEIN, FOUNDER, NEW YORK STATE PARENT COMMITTEE FOR THE EDUCATION OF CHILDREN WITH HANDICAPPING CONDITIONS, AND LEGISLATIVE CHAIR, PARENTS' ASSOCIATION, NORTH SHORE UNIVERSITY HOSPITAL PRESCHOOL AND INFANT DEVELOPMENT PROGRAM

Ms. **Rubinstein**. Good evening, Mr. Chairman. Thank you for the opportunity to speak before you. First and foremost, I'm Becky's mom. My name is Jane Rubinstein. I'm a person who advocates at every opportunity and at every possibility and on every level available.

I am the founder for the New York State Parent Committee for the Education of Children with Handicapping Conditions. I'm the legislative chair for my Parents' Association at the North Shore University Hospital Preschool and Infant Development Program. I'm an active member of SEPTA at both my district and district council and an officer-elect in the coming year.

I've been participating three years on the Nassau County Regional Planning Group in planning for the New York State Early Care legislation, and in that capacity serve on the executive committee and have co-chaired committees on professional sensitivity and on funding issues. I've participated for the past three years in the New York State Perinatal Association. And if you know of any organizations I've missed, I'll be there.

As I said, first and foremost I'm Becky's mom. I had the opportunity to author an article which was published by the New York State Association of Counties in their news forum in the November/December 1989 issue. And I started that forum by saying, there's a saying in social settings that one child is a tragedy, a thousand are statistics. And I am driven not to let Becky and each and every one of the children involved become statistics.

Because as heartened as I was to hear the testimony of the many professionals that preceded us, I began to get the feeling we were talking of statistics. I'm here talking about Becky. And I'm here talking about all the other babies in the neonatal intensive care units and in the early intervention programs; the children that I deal with daily as a parent advocate on my Committee on Preschool Special Education and on my Committee on Special Education that I've served for the past two years.

Just a moment in terms of Becky and her history. Becky was a 990 gram preemie delivered at 26 weeks, 5 days pregnancy, and if you've ever seen a baby that small, she was less than 14-inches, her leg was as thick as my forefinger. She stayed in the hospital for 6 months and 3 days, she was on a respirator for nine weeks, and on oxygen for 3 months.

During that time she suffered brain bleeds, lung damage, rickets, fractured bones. She is now diagnosed with mild CP. She still continues to suffer the side effects of bronchial pulmonary dysplasia which was a side effect of respiratory distress syndrome. She is generally developmentally delayed although we can no longer take credit or solace in that general descriptive.

And she has been receiving early intervention services since she was an infant residing in the NICU.

And I thank my lucky stars that she entered the system under the New York State Family Court System and does not have to suffer the forthcoming early care system. She has benefited greatly and she's made great strides and advances. She is transitioning to the school age system this year and will suffer terribly because of it, because of how New York State continues to implement early intervention and special education in the name of cost containment and mandate relief. It is a frightening experience.

I mentioned that I authored an article in 1989 and that article has been appended to Mr. Held's testimony which has been submitted to you earlier. And many of the concerns that I expressed in that article two years ago hold true to this day.

I feel that early care will be adopted and forced ahead in this year in New York State as part of a contrived crisis rather than as a planned response to wonderful Federal initiatives, because that's exactly what happened with the preschool initiative. There was a contrived crisis, it was forged ahead, and it was only through the efforts of parents such as myself and the New York State Parent Committee that negotiated long and hard to maintain the modicum of parental choice and involvement that we continue to exert today.

There are a number of issues that remain. And the first and foremost in my mind in New York State is to fix the split. When the governor chose to implement Part H, he split the birth-3 and 3-5 populations by designating different lead agencies, and it seriously fragmented the continuum of services with the ultimate loss, that being the loss of parent choice and involvement. And so in Federal reauthorization there must be language and assertions to the State that they must provide an appropriate continuum.

I don't care what agency manages my child's services but I will be gosh darned if that division of authority results in a fragmentation of services to a very fragile young population.

Therefore, there must be a basis for transitions from birth-3 and to preschool. There must be common definitions across agency lines so that there's a commonality that allows that continuum to proceed. There must be the opportunity for co-service of toddlers and preschoolers in the same program.

If it were not for my individual advocacy at the governor's office, New York State Education Department indicated that would not fund tuition for a preschooler in a toddler class because they simply didn't want to deal with two agencies in one classroom.

And I argued, thankfully successfully, that if two children ages 2 and 3 have similar needs and are appropriately placed in certified programs with approved tuition, there was no preclusion to them being co-served. And so they entered the Becky provision in Chapter 243. And unfortunately, when the Early Care Bill passes there will no longer be a provision for that connection. So you will have children transitioning physically, as well as administratively, when they transition from age 2 to 3.

And it's such a critical year because there are so many children who have neurologic problems or speech impaired problems, who are not readily identified at birth as my child was, who are just becoming diagnosed and identified in that critical period between age 2 and 3. And so you're taking a very fragile population and causing them this very artificial transition.

Mr. Held introduced the concept of maintenance of effort and I think it's essential. I was heartened in reading the Federal legislation of the philosophy that dollars were to be supplemented not supplanted.

But besides maintaining dollars, I believe, even more importantly, services must be supplemented not supplanted. There must be a basis for comprehensive services—which are a model of excellence in New York State and that already exists—to continue.

I'm very concerned about the forthcoming early care legislation which is advanced primarily on a medical model. The medical model saved my child's life for six months in ICU but now we're talking about skills for development and skills for living and skills for learning.

And it is a fragmented system if we are talking about clinical threshold visits. Just because they're under one roof does not make it a comprehensive program. And I fear for children who can barely integrate their learning skills and their own development if they must integrate fragmented services on their own.

There are several areas that, unfortunately, the Federal legislation is lacking in. It provides the opportunity for third party payment and particularly in segments of the population where poverty is a very real issue.

The availability of Medicaid is key and important in providing so many essential services. But unrecognized is the impact it has on the middle-income families. Medicaid is the payer of last and therefore, middle-income and lower middle-income, many blue collar working families who have private health insurance will be forced to utilize that insurance for early intervention services for their children.

And I can tell you the firsthand stories of parents and whole companies who have lost their insurance coverage based upon the early medical needs of their child. My child incurred half a million dollars of medical expenses in the first year of life and thank goodness I had the insurance to cover it.

But, for families who have marginal insurance carriers, because it was a small family-owned business, the entire company, and therefore many people, lost their insurance coverage because the insurer chose not to underwrite that firm any longer. The family then enters a new insurer with preexisting condition exclusions and the entire family is placed at-risk for medical crises.

And so it is unfortunate that the Federal legislation does not address the issue of protection to families in terms of annual lifetime caps when private insurance resources are used before Medicaid can be accessed for those families.

Another area that is unfortunately lacking and scares me a great deal with respect to the early care legislation is the issue of confidentiality. Early intervention is a non-compulsory system. Until the child becomes school age the parent need not, although we certainly all agree they should, participate, and so a family is very concerned about the issue of confidentiality.

As a preschool parent I can rely on the Buckley Amendments to protect the records of my child. But, what will happen to the infants and toddlers particularly given New York State's assignment of that jurisdiction to the Department of Health? Does that child become protected under the medical model of confidentiality which significantly differs from the educational model?

I believe there must be a standard for confidentiality with the associated penalties and authorizations under the Buckley Amendments that protect preschool and school age children.

I mentioned before the need for a maintenance of effort. There are models of excellence in New York State and they must be supplemented not supplanted. That must be a condition of funds—prior to legislation in New York State or elsewhere—that there continue to be a maintenance of effort involving parents.

It concerns me that in New York State, because it has not yet adopted legislation, and I again reiterate, I am not rushing the legislation in response to contrived prices, there must be the continued input of parents through the regional planning groups or other venues. I am very concerned each time I see revised drafts. And although New York State is attempting to maintain the family focus, it is only families that can truly speak to the issue.

And I would much more certainly appreciate participating in a regulatory and legislative process than fighting it the way I had to do in an adversarial manner with respect to Chapter 243 in the passage of the preschool legislation.

Family court is a wonderful process because it provides the ultimate due process, family choice. If the program doesn't work you seek out another. There are wonderful early childhood direction centers which make unbiased and vast recommendations to families. And in remembering that it's a non-compulsory system, we must respect the family to accomplish the desired goals: early intervention not intimidation of families.

I'm particularly concerned about things that have happened in New York State. Commissioner Gloeckler's statement, which I read at the top of the auditorium, indicated that it's a complex process and taking a great deal of time in New York State. But, I fear that there is a dismantling of the existing system, not enhancing it, in implementing the new administrative structure.

Chapter 243 fragmented families from the system; it created an intimidating and adversarial setting. Parents are now held from being a team member with their evaluator. It's become truly adversarial. It shames me that I attended a State Education Department training session in which I was in a room primarily with school districts with a State Education trainer advising school districts, "you know what providers you like to work with, steer your parents; you can tell them where to go so that they go to the programs you are more comfortable dealing with." I was abhorred. This was the parent choice and the parent need that we fought so hard for.

Another parent reported to me that State Education said, "sure if we change the handicapping classifications we may be out of compliance with the feds but it will take them two years to catch up with us and we'll save 1.5 million in the process."

I fear for the very life of my child. And whether that's rumor or fact, it is clearly indicative of the fiscal environment New York State is in now. The rumors are flying so fast, I can't tell them from the truth.

It is clear that New York State is restricting eligibility all in the name of cost containment and mandate relief. There are proposals to delete classifications such as other health impaired, multiple handicapped, orthopedically impaired, that they would make the educational criteria so restrictive that unless a child exhibited an IQ of 70 or below, he/she would be ineligible for services.

I find it amazing and remarkable that my Becky, my tragedy, not a statistic, is at risk for services next year. Because, she has made such wonderful gains and because she participates so well with an adult on a one-to-one setting. She has tested remarkably high on her IQ potential test.

But you put her in a class of ten children, she becomes dysfunctional and dysfluent. She loses her gross motor skills; she loses her fine motor skills; she loses her toileting skills, she loses her ability to speak. This child cannot function in a regular classroom.

But because of the manner in which New York State is implementing cost containment, she is at-risk on whether she will receive any services next year. And what is even more disgusting is that it is being done outside of a legislative process. It is being done through the Board of Regents who is not responsive to the legislature and therefore not responsive to families as voters, so I cannot even participate as a voting member of the public.

It further removes parents from the very essential role they play in the care of their children. Early intervention is a Godsend. It has absolutely made a child I call Becky into a functional, warm, happy child who will be a productive member of society. But it is a sin that I have to fight so on so many avenues to make sure that the system works for her. There are parents far less capable than I.

And so I request that as you embark on your Federal initiatives that you oversee the States to make sure that the abuses that are happening at a very real fiscal crisis do not become a crisis of the children. Thank you.

[The prepared statement of Jane E. Rubinstein follows:]

# POLICY REVIEW FORUM

## LEGISLATING EARLY INTERVENTION SYSTEMS FOR INFANTS & TODDLERS

## THE PARENTAL PERSPECTIVE

by

Jane E. Rubinstein, Vice-Chair

New York State Parent Committee for the
Education of Children with Handicapping Conditions

There is a saying in many social services settings... "One child is a tragedy... a thousand are statistics". The role of a parent is to ensure that their child is treated as an individual, with individual needs, and not as a statistic.

We, as parents, are the best resources and advocates for our children. As such, the role of **PARENTS AS EQUAL PARTNERS** with government, and providers of services must be maintained. Parents must be involved participants and not be limited to a bystander role. Early intervention services are not compulsory. The more involved parents are in the process, the more effective the system will be, as expressed in greater participation and carry-over in the home. Parents have been unfairly characterized as too fragile and emotional to serve the needs of our children. It is an unwanted and inappropriate stigma.

Through sharing our experiences with the Family Court system, we recognize the admitted discrepancies in the provision of services through the state. While legislating a new system in accordance with PL 99-457, care must be taken to preserve the significant attributes found in the current system, in the optimal provision of services in some localities, and in the extensive and evolving knowledge of early intervention professionals with respect to program scope, content and efficacy.

One of the specific concerns of parents is the need for an **EFFECTIVE CONTINUUM OF SERVICES**. In 1986 when Governor Cuomo designated the Department of Health (DOH) as Lead Agency for infants and toddlers (birth - 2.11), and the State Education Department (SED) for preschoolers (3 - 5), the current service system under Family Court for birth-to-five suffered immediate fragmentation against the wishes of many parents and professionals. However parents are far less concerned with what agency administers our children's services than we are with obtaining fully integrated services during the critical formative years, birth-to-five.

We urge the State to **FIX THE SPLIT** created by bifurcated legislation and administration. Legislation and regulation cannot simply rely on transitional services to bridge two systems. To truly sustain the integrated services now available in the Family Court System involves, at a minimum the following efforts. The first is integration of policy, legislation, and regulation from the top down. There must be close coordination and inter-agency involvement, particularly between DOH and SED. Unfortunately, despite repeated requests, SED has failed to appoint a formal representative to the DOH State Interagency Coordinating Council.

The two service systems must be based in a common orientation and philosophy and, therefore, pragmatically share common definitions across administrative lines, i.e. on issues of eligibility, personnel development, program approval. A more specific concern is that infant/toddler legislation must enable, and the preschool legislation must be amended to make permanent, co-service of two and three year olds in common classrooms or service settings. Based on the varying physical, emotional and developmental maturity of toddlers and preschoolers, it is not only appropriate, but probable that some 3-yr olds should remain with younger children, and some 2-yr olds should be advanced. The State must not allow parochial administrative issues to preclude effective programming for children with widely varying rates of progress. If programs are equally approvable by DOH and SED, and rates are set in accordance with approved methodologies, the definitive factor must be the best interest of the children.

Furthering the concept of **COMPREHENSIVE SERVICES**, we applaud DOH's expansion of the targeted service population through wider definitions of at-risk and developmentally delayed. To meet the needs of this growing population, services must be maintained in settings which enhance early intervention/diagnosis/remediation. Children and their progress are not static. We, as parents can best attest to the transition and flow of our children's conditions. If the focus of early intervention services becomes discretionary services in non-programmatic settings or in threehold clinical visits, we will suffer the ability to provide timely, fluid responses to either additional or reduced therapy needs.

The DOH model for the proposed system must be flexible and simultaneously permit the educational and medical responses based upon the pendulum of an individual child's needs. Restricting services to a medical model will be devastating to the advances made in early intervention programs over the past twenty years, and will impede the development of services in rural or developing areas of the state.

A commitment to quality services must be demonstrated by DOH and the State through a parallel and substantial effort to **DEVELOP PROFESSIONAL STAFF**. We parents clearly see the need for more trained therapists, teachers, and family counselors. Our children, first-hand, have suffered from a high rate of staff turnover, randomly in mid-semester, or from reliance on non-certified, less experienced personnel. The availability of properly trained staff, in all areas of the state, is currently the weakest link in the service provision system and must pragmatically be addressed.

If there is one issue which is most frightening to parents and families, and makes us feel more vulnerable than any diagnosis, it is **THIRD PARTY PAYMENTS**. The federal regulations are remarkably lacking in any substance or guidance on private funding sources, particularly with respect to safeguards for a family's financial resources. It is all too common for an infant, medically involved from birth, to encumber half-a-million dollars or more during the first year of life. Annual and lifetime caps are readily met affecting either the individual child or the entire family, placing the health and welfare of two, three, four or more individuals at risk. When insurance is provided through small, or family-owned businesses, insurers have elected not to renew an entire firm's policy. Subsequent underwriters impose significantly higher premiums, reduced coverage, and extended exclusions on pre-existing conditions.

Our last concern is generally **LEGISLATION WITHOUT REGULATION**. We are weary of proposed laws which enable services, in the absence of draft regulations. Arguably regulations must follow legislation, however DOH representatives have expressed some troubling agenda which will only become explicit in regulations. It will be those regulations that will become "the bible" of our children's daily lives.

Of all the involved parties and parochial interests in the legislative process, ours is the greatest. We parents bring to the forum our thousands of individual stories who we will not allow to become statistics.

**Chairman Owens.** Thank you very much.

We started with testimony from State officials. I think it's altogether fitting and proper that we end with your testimony which provided us with some critical analysis of what one parent thinks is happening at the State level.

I want to thank all of you. Your statements will be entered into the record along with the others. If you have additional written statements that you'd like to submit, we'd be happy to receive those in the next ten days.

Thank you very much.

[Whereupon, at 7:07 p.m., the subcommittee adjourned, subject to the call of the Chair.]

[Additional material received for the record follows.]

Statement of

Theadora de Soyza

Member of the New York Association for the

Education of Young Children and

Council For Exceptional Children

and

Executive Director

Miriam de Soyza Learning Center

to

Honorable Major R. Owens, Chairperson

House Subcommittee on Select Education

on

Hearings on the Reauthorization

of the Early Intervention and Preschool Program

Under the Individuals with Disabilities Education Act

P.L. 99-457

May 6, 1991

Mr. Chairman and members of the Subcommittee:

I am Theadora de Soyza, Executive Director of the Miriam de Soyza Learning Center and parent of a child, Miriam, who had Down Syndrome and lived four short years (from 1971-1975). My husband, Dallas, and I founded one of the first early intervention programs in the Bronx for children with disabilities from birth to five years of age. Since 1971, this STate of New York has seen a proliferation of such programs which have helped prevent institutionalization of children; have kept families together and have provided the necessary support system essential to raising a child with a disability. On behalf of my families living in the South Bronx, I support the reauthorization of the Early Intervention and Preschool Programs under the Individuals with Disabilities Education Act (IDEA, 1991).

These are several areas of concern regarding the implementation of this program in our State of New York. These include:

1. the impact on parental choice
2. the erosion of regional municipal authority based on New York's interpretation of P.L. 99-457.
3. New York's ability to redefine eligibility criteria based on its interpretation of P.L. 99-457 eligibility categories.
4. the need for a "Maintenance of Effort" provision in the Federal Law.

After passage of the Education of All Handicapped Children Act of 1975, New York State passed the Family Court Act #261. This law gave parents the right to choose a program which they felt secure enough to leave their

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delicate and fragile child for evaluation and programming for a few hours each day in most cases. In addition, the responsibility of the administration and accountability of this program was placed with the municipality in which the child resided. The overall programmatic authority was with the State Education Department. There were also 14 "Child Find Direction Centers" financed and administered throughout the state by the State Department of Education under this system, though not perfect, parents were, for the first time, empowered to make choices; local private agencies developed creative and innovative programming which helped meet the needs of both children and families. Wisely, localities throughout the state developed regional implementation regulations in order to ensure accountability and program integrity.

Since the passage of the Governor's Bill in the form of Senate Bill 6374 and Assembly Bill 8816 in June 1989, the system which replaced the one which served many children has deteriorated into a veritable nightmare due to the following reasons:

1. Cumbersome Apparatus:

   Under the Family Court System, children with disabilities and those deemed high risk would be referred by diagnostic and evaluation clinics. There would be an intake at the preschool agency and the child could enter the program within two weeks. An Individualized Educational Program

I. Cumbersome Apparatus (cont'd):

(IEP) was in place after assessment and observation. Since the preschool child is a unique little creature, observation of the child in the classroom environment is most important when developing the IEP. This theory is substantiated by early childhood educators. Piaget's whole education theory was developed through observation.

Under the new system, an incredible bureaucratic monstrosity has been created. Not only is it burdensome to many parties, it is not cost effective; it is very expensive. The papers required on each child could decimate our forests.

There are three levels of auditors, two city monitors and contract and unit monitors, one monitor and three evaluation monitors. Each school district has a committee for preschool special education and a centrally based support team. All three levels evaluate the child's assessment package. There are three levels of program assistance: The New York City Department of Health and Day Care; the State Education Department and the New York City

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Board of Education. It sounds more like a penal system; the next step being a jail sentence. They spend their time scrutinizing every sentence and are delighted to slap a non-compliance on us when, very often, we were not informed previously to providing a service. Very often the monitors themselves are in disagreement regarding the implementation of regulations.

2. Descriminatory:

as you can see, this system is froth with descrimination in the guise of insuring services to children and families. Nonsense! The typical child can enter the public school system simply by going to the local school, register for September and enter in September. Our children need proof upon proof; need scrutinizing at three levels and then if they are lucky, they will start in September. Many start in November or December. This is certainly not in the best interest of a handicapped child who needs early intervention as early as possible. Today we have more children "at-risk" than even before due to crack, cocaine, and polydrugs. Help save the children!

Fragmentation:

New York has chosen to separate the disabled into two groups, birth through age 2.7 years under the New York State Department of Health and 2.7 to 4.9 years under the State Education Department and New York City Board of Education. This system places an additional burden upon parents who must go through another maze of bureaucracy. These parents are just beginning to deal with the fact of having a disabled child. They must go to their local school district when the child is 2.7; choose an evaluation site; go the evaluation site for evaluations; wait for a meeting to be called by the CPSE and wait for approval by the CBST (Central Based Support Team). Under the previous system, children moved smoothly from an Infant/Toddler Program into the three to five program with all the necessary re-evaluation procedures. This system insured the rights of both parent and child as well as insuring continuity of programming and staff.

In conclusion, I am asking you, Senator Owens, to help save the children. Governor Cuomo is seeking to further restrict eligibility criteria so that thousands of children will not receive the services which are critical to their growth and development. A very shortsighted view since in the long run, more dollars will be needed for mental health institutions, prisons and welfare.

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I am attaching some very frightening statistics which the Children's Defense Fund has published regarding the nation's children. Save the children! Save the cities! Save the nation! What a unique nation we could be if only we had the WILL!

Testimony Addendum
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## LET THE STATISTICS REVEAL THE TRUTH

- Everyday 135,000 children take a gun to school.
- Every 35 seconds an infant is born into poverty.
- Every 2 minutes an infant is at low birthweight (less than 5 lbs. 8 ozs., or 3 lbs. 8 ounces), becoming high risk for developmental delays.
- Every 14 seconds an infant dies inthe first year of life.

## AMERICA'S POOR CHILDREN

Out of 100 poor children in America:

- 41 are white, non-Latino
- 35 are black
- 21 are Latino
- 3 are Asian, Pacific Islander, Native American or Alaskan Native.
- 38 live in married-couple families
- 54 live in female-headed families
- 28 live in families headed by persons younger than 30
- 11 live in families headed by persons younger than 25
- 28 live in suburban areas
- 27 live in rural areas
- 45 live in central cities

The Food Research and Action Center reports that 5.5 million children in the United States are hungry. One out of 12 are under the age of 12.

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STATEMENT

of

Robert and Donna Owens

Parent of a Disabled child attending

The Miriam de Soyza Learning Center

to

Honorable Major R. Owens, Chairperson

House Subcommittee on Select Education

on

Hearing on the Reauthorization

of the Early Intervention and Preschool Program

Under the Individuals with Disabilities Act

PL 99-457

May 6, 1991

[illegible]

[illegible] children with handicapping conditions. The children we speak of are pre-school infants and toddlers (birth thru five years of age). I need not tell you the importance of a child's development during the early years of his/her life. And a child who is handicapped has an [illegible] need for a positive, stimulating, nurturing environment during the early years; in fact the need is [illegible]. The handicapping condition places [illegible] therapeutic, medical [illegible] still address the needs of the other family members.

[illegible]

[illegible]

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[illegible]

[illegible] we only wanted the best for our child. Yet in our path the Bureaucracy applied delays. When we began the search for the appropriate school setting, [illegible], we were informed by the Eunice K. Kennedy Center for Child Development, that there were [illegible] such programs for [illegible]. Where does one begin?"

Thanks be to God, Mr./Ms. Chairperson, that we are who we are; and together we had enough hope, intellect, strength and support, coupled with the most radiant smile from [illegible], to forge ahead and negotiate the system and maintain our sanity, our relationship as a family, and our [illegible]. We were also able to place [illegible] in an educational setting which we thought would be appropriate [illegible] For the record, a handicapped child must have a parent do all of the leg work (take him/her to doctors appointments, complete [illegible] of interviews, etc.) and [illegible]

[illegible]

[illegible]

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of a need within the Board of Education for Special Education personnel. As an educator myself, holding a Master's Degree, I have questions about the Board of Education's dealings with children of pre-school age. Looking back, curriculum started with kindergarten.

Robert and I come here today to ask that special attention be given to infants and toddlers with handicapping conditions. The work and effort that we have expended on behalf of our daughter is because we love her, and we realize that she is one of God's creation, in His image. We also believe that although our child is handicapped, she has the potential and the ability, with the proper education, love and guidance to become a productive woman in this society. We, further ask, that representatives from this City Council of New York, and the Mayor, David N. Dinkins venture out to the Bronx to see what the staff at the [illegible] Learning Center is doing to contribute to equipping young ones for our city. Lastly, we plead with the representatives here, to review the procedures for evaluating children in handicapped programs, and look at the operation of the small programs which seem to be providing more than a school for the child, but a total program for the family, which for many is the only way to survive when you have a handicapped child.

Respectfully submitted,
Robert & Dona Marie [illegible]
825 [illegible] Avenue #[illegible]
Bronx, New York [illegible]
(212) [illegible]

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